

Appendix 1: Focus Group Moderator's Guide

02/28/2011

Moderator's Guide: HIV Vaccine Research- Formative Research

Groups and Locations

| | Hispanic Men | Hispanic Women | African American Men | African American Women | MSM | Trans-gender (18+ yrs, any race/ethnicity) | TOTAL |
|----------------|--|--|-----------------------------|-------------------------------|---|---|--------------|
| NYC | 1 (26-45 yrs, English speaking) | 1 (26-45 yrs, Bilingual-Engl/Spanish speaking) | 1 (26-45 yrs) | 1 (26-45 yrs) | 1 any race/ethnicity (26-45 yrs) | 1 | 6 |
| Miami | 1 (45+ yrs, Bilingual-Engl/Spanish speaking) | 1 (45+ yrs, English speaking) | 1 (18-25 yrs) | 1 (18-25 yrs) | 1 Hispanic (18-25 yrs) 1 Hispanic (26-45 yrs) | - | 6 |
| Atlanta | 1 (18-25 yrs, Spanish speaking) | 1 (18-25 yrs, English speaking) | 1 (45+ yrs) | 1 (45+ yrs) | 1 African American (18-25 yrs) 1 African American (26-45yrs) | - | 6 |
| Oakland | 1 (18-25 yrs, English speaking) | 1 (18-25 yrs, Spanish speaking) | 1 (18-25 yrs) | 1 (18-25 yrs) | 1 any race/ethnicity (18-25 yrs) | 1 | 6 |
| TOTAL | 4 | 4 | 4 | 4 | 6 | 2 | 24 |

Objectives

- A. Assess current HIV vaccine research knowledge and attitudes**
 - Identify and prioritize existing myths/barriers
- B. Explore preferences for materials development and dissemination**
 - Current and preferred sources of HIV vaccine research information
 - Preferred channels for HIV vaccine research information
- C. Explore concepts/themes**
- D. Test "Be the Generation" materials (if time allows)**

Public reporting burden for this collection of information is estimated to average 120 minutes per response. This time includes the length of time allotted for a focus group. 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: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN; PRA (0925-0585). Do not return the completed form to this address.

Introduction: Welcome (10 minutes)

- A. Purpose: The main purpose of our discussion is to talk about HIV vaccine research.
- B. Disclosures
 - Observation
 - Audio taping
 - Measures for safeguarding privacy
 - Discussion will last about two hours
- C. Ground rules
 - Need to hear from everyone; one at a time please
 - No right or wrong answers
 - Moderator is impartial, please be candid
 - Moderator cannot answer questions about HIV or HIV vaccines (will provide references to reliable sources of information at the end of the discussion).
- D. Participant introduction
 - Your first name only
 - What do you like to do for fun?

Issue A: Current HIV vaccine research knowledge and attitudes

(40 minutes)

1. When you see this phrase what do you think of?

Moderator to write “ending HIV” on flipchart and record responses

Probe:

What comes to mind when you think of this?

Moderator to take note of barriers and myths for prioritization exercise

2. When you see these words what do you think of?

Moderator to write “HIV vaccine” on flipchart and record responses

Probe:

What are some things that you have heard or seen about HIV vaccines?

Moderator to take note of barriers and myths for prioritization exercise

Just to make sure we all understand, let me explain that HIV vaccines are an ongoing area of research. The goal is to develop a vaccine that will prevent HIV, just like we have vaccines to prevent diseases like polio and mumps. This research depends on participation of volunteers who do not have HIV.

3. Suppose that an HIV vaccine research study was being conducted and individuals from your community were being recruited to participate. What would be your reaction to the research study?

Probe:

What questions might you have about the research?

Would you have any concerns? If yes, what concerns would you have about the research? Are there any other things that you believe would influence your opinion about HIV vaccine research, or might influence the opinions of others in your community?

Continue to probe until respondents run out of suggestions.

Moderator to take note of barriers and myths for prioritization exercise

Prioritizing Exercise

[Additional probe for barriers, if necessary] Let's assume that there are people who wouldn't be supportive of HIV vaccine research. What may be some of the concerns?

Moderator lists concerns on the flipchart and labels them A-Z. Once all participant suggestions have been offered, add any other barriers/problems/reasons/myths that were introduced earlier. Do not mention any barriers that were not already mentioned by the group. Once all items are listed, move on.

Let's look at the list we have compiled. I want you to take a few minutes to rank these concerns from the strongest to the weakest. The piece of paper I am handing out has a bull's eye on it. **DON'T PUT YOUR NAMES ON THE PAPER.** The center of the bull's-eye represents an **EXTREMELY STRONG**

REASON. **Moderator shows an example of a completed bull's eye.** If you put a reason in the center that means this concern is so strong that you would not support HIV vaccine research studies. The further you move away from the center, the less of a concern it is, and the area outside the bull's-eye is considered a very weak concern. Please write the letter associated with each problem on the bull's eye to note how strong you think it is.

(Once respondents have completed the activity)

4. Let's discuss the way you prioritized the reasons. Did anyone place something in the center of the bull's eye? (Again, this means it's a reason so strong that you wouldn't support HIV vaccine research.)

Probe:

What makes this such a strong concern?
Is there anything that can be done to reduce that concern?

5. Were any concerns placed in the middle three rings of the bull's eye? What makes these concerns only somewhat strong?

Probe:

Is there anything that can be done to reduce that concern?

6. Were any reasons on the outside of the bull's eye, meaning they pose less of a concern?

Probe:

What makes these concerns less important to you?

[Moderator collects bull's eyes]

7. Let's go back to what we were talking about earlier-- ending HIV. Are there any benefits for you, or someone like you, for participating in research to test an HIV vaccine?

Probe:

What are these benefits? Why should someone participate?

8. Now I'm going to read you some statements about HIV vaccine research. Listen carefully and think about what your reaction is to these statements. **[Moderator reads the following]**

- Research is being conducted to find a safe and effective vaccine that would prevent the transmission of HIV.
- Currently, a preventive HIV vaccine does not exist.
- The HIV vaccines used in research studies cannot cause HIV infection or AIDS.
- HIV vaccine research study volunteers are never exposed to HIV by the researchers.
- Finding vaccines that help prevent HIV infection can benefit every community because HIV knows no boundaries.
- The safety of research volunteers is always the top priority in HIV vaccine research.

What's your reaction to this information?

Probe:

Do you believe it (i.e., do you think it's scientifically accurate)?

Probe for authority, credibility, good role model.

If no, which part do you believe or not believe?

Continue to probe until respondents run out of suggestions

9. Are there other questions you have about research for an HIV vaccine that we haven't discussed yet?

[Moderator adds as necessary] Please remember that I don't have the answers (I'm not a doctor), but it's important that we collect the questions for the experts to address.

Issue B: Materials development and dissemination

(35 minutes)

1. **[For groups familiar with HIV vaccine research]** How have you heard or learned about HIV vaccine research?

Probe:

Have you gone somewhere to get information about HIV vaccine research?

Have you ever come across news or information about HIV vaccine research? **If yes**, where?

Who has been the source of this information?

Was it a good source of information?

How do you decide if this is a good source?

2. **[For all groups]** Let's go back to a situation where someone you care about, like a sister/brother/friend said they were interested in participating in an HIV vaccine research study, but they wanted more information. Where would you advise them to look for information?

Probe:

Who would you advise them to talk to, or which sources of information would you recommend?

[If not discussed previously] How do you decide if this is a good source?

3. If new educational materials were to be developed to inform you and your family/friends about HIV vaccine research, who or what organization do you think would be a good source?

Probe:

Who or which organizations do you tend to trust for information on health and medicine?

[Moderator lists sources on flipchart, and prompts "U.S. Government" and other organizations listed on "Ranking Sources of Information" sheet, if necessary. Moderator can emphasize that it is not necessary for everyone to agree on which sources are trustworthy.]

Once the group has created the list, moderator distributes "Ranking Sources of Information" sheet. Moderator marks on the flipchart any sources mentioned by the group that are not on the sheet.

On this sheet you will see we have listed many of the sources we discussed. Now I'd like for you to take a few minutes to rank all of the sources listed on the scale at the top. **[Shows example]** For example, if you think a health care provider is a source you trust strongly, you would mark the square in the right

hand column. If you're unsure of whether information coming from health insurance companies are trustworthy or not, mark the middle column.

Please write in these sources that I've marked on the flipchart in the blank spaces at the end of the list. Please take a few minutes to do that now.

4. Now that we have finished ranking the organizations, which people or organizations did you rank as being trustworthy sources of HIV vaccine research information (in the right-hand column)?

Probe:

What makes those sources trustworthy?

Did you add any other organizations that you would like to get HIV vaccine research information from? **If yes, Which? Why?**

5. Which organizations or people were listed as those that you do not trust for HIV vaccine research information?

Probe:

Why don't you trust those sources?

[Moderator collects sheets]

Now I'd like to talk a little about how you prefer to get information about HIV vaccine research studies. I am putting pieces of paper with words or phrases on the wall. **Moderator to read words as they are placed on the wall.**

Words or Phrases include: radio, television, newspaper, Internet, email, community (meeting, event, health fair), doctor's office or clinic, school, place of worship, and other.

Please take a minute to look over these different ways to receive information about HIV vaccine research. I am giving you green and red stickers. I want you to go around the room and put red dots under ways you would NOT want to receive information about HIV vaccine research and green dots under the ways you would want to receive HIV vaccine research information. **Moderator to show flip chart page explaining colors.** There is also one sheet that says "other." Please add suggestions of ways you would like or not like to get information to the list. Make sure to put the appropriate colored dot next to your suggestion. Please take this time to put dots next to each of the items.

Once the group has finished putting up their dots, talk about the two items that had the most green dots and the two items that had the most red dots.

6. Now that we have finished it looks like **X** was the most popular way to receive information. For those who selected it, what makes you prefer to receive information this way?

Probe:

What makes this way better than other options?

Repeat for second most popular.

7. X was the least popular way of receiving information. For those who selected it, what makes this the least desirable way to receive information?

Probe:

Why do you dislike this way more than other options?

Repeat for second least popular.

8. **If suggestions were added to the “other” list, go through list to see why individuals included those items on the list.** Now let’s look at the list of “others.”

Probe:

What makes this a good way to get information?

What makes this a bad way to get information?

9. **Once moderator has gone through the list, or if nothing was added to the “other” list.** Are there any other ways you would like or not like to get information about HIV vaccine research?

Probe:

What makes this a good/bad way to get information?

Issue C: Concept-Theme Testing

(25 minutes)

Next we’re going to look at some ideas for different materials or campaigns about HIV vaccine research. Keep in mind that what I’ll be showing you tonight are just some basic ideas. We’ll be looking at four different themes that could later be turned into a series of educational materials.

Hand out Concept A and read aloud to the group.

1. What do you think of this theme?

Probe:

What does it tell you about HIV vaccine research?

How interesting do you find this message? Very interesting, somewhat interesting, or not at all interesting?

How relevant is this theme to you?

Is there anything you would change about this message to make it better?

Repeat for concepts B-D

When finished discussing all 4, write letters A through D on flip chart.

2. Now, I’d like you to pick the theme that would be most likely to make you feel positive towards or

supportive of HIV vaccine research.

3. Let's go through and see which messages were picked. How many of you included message A as most important to hear when thinking about HIV vaccine research? **Tally on flip chart. Continue through Message D.**
4. **After tallying is complete** What made you pick this concept?

Probe:

Is there something that made you more interested in this concept?

Repeat for all concepts

Issue D: Be the Generation Materials Testing (if time allows)

(5 minutes)

Give participants a copy of brochure, mini-brochure, and fact sheet. Display poster.

1. I want to share some draft materials with you. These materials have been developed for **[insert group]**. They come in a variety of formats: a brochure, mini-brochure, a fact sheet, and a poster. What do you think of these materials?

Probe:

Which (if any) do you think you would be more likely to look at? Why? What makes that item more appealing?

How relevant is this concept to you?

Is the information in these materials easy to understand?

Is there anything you would change about this item to make it better?

2. I want to share some examples of the different materials that were created for different audiences. **Show poster in different versions.** What do you think of these materials?

Probe:

Which version do you like better? Why?

Issue E: Conclusion

(5 minutes)

I'm going to check with my colleagues to see if there are other questions they want me to ask. While I'm doing that, I'd like you to discuss with each other and see if you can agree on an answer to this question: ***what do you think would the most frequently asked question or concern about HIV vaccine research among your family, friends and/or community?***

- A. Check with clients for additional questions or comments
- B. Thank and dismiss participants
- C. For additional information, please visit: <http://www.bethegeneration.org/>

Ranking Sources of Information

Please rank each source of information on HIV vaccine research from 1 to 5 by checking a box under one of the numbers.

A check under the number 1 that means you believe that the person or organization is very untrustworthy. Checking the box under the number 5 means you believe they are very trustworthy.

| | 1 | 2 | 3 | 4 | 5 |
|--------------------------|---------------------------------|--------------------------------|---|------------------------------|------------------------------|
| | I strongly distrust this source | I don't trust this source much | Unsure whether or not I trust this source | I trust this source somewhat | I strongly trust this source |
| Health care provider | | | | | |
| Health insurance company | | | | | |
| Federal government | | | | | |
| State government | | | | | |
| Local government | | | | | |
| Religious leader | | | | | |
| Community organizations | | | | | |

Locale:

Session:

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