Sample Focus Group "Script" or Discussion Guide

For PLWH Who are Out of Care or Recently Entered Care Focus Group

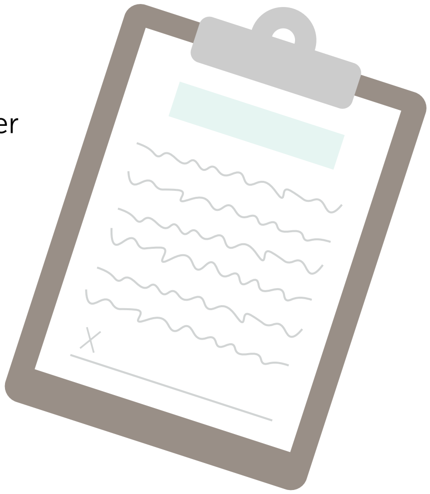
Note: This is the "general script" for a series of focus groups and assumes the focus group will be conducted at a physical location. Specific information for particular subpopulations – e.g., young African American MSM, Transgender PWH, recently incarcerated PWH – will need to be added, and the whole script adjusted to ensure culturally appropriate language for each group. The script will need to be translated and further revised for use in Spanish or another language. If the focus groups are conducted remotely, it may be desirable to eliminate 1-2 questions to keep the total length below two hours, some instructions will change, and the demographics questionnaire might be replaced with polling (conducted late in the session, so participants are comfortable providing the information).

As participants arrive

Greet participants as they arrive. Get their names and check them off using your master list of participants. Ask them to take a seat and make themselves comfortable. Point out refreshments, and encourage them to help themselves.

Distribute the demographics questionnaire and ask participants to complete it while they wait for the focus group to begin. Explain that the questionnaire will provide us with information about their background, and that this information from all participants will be combined to provide a profile of the whole group. Tell the participants that you will never use any identifying information such as their name, or identify them as clients or a particular agency, in any of our reports. Offer to "interview" participants who would prefer this to filling out the questionnaire.

Distribute the consent form for participants to review and sign.



Introduction

1. Introduction of facilitator/moderator and note taker

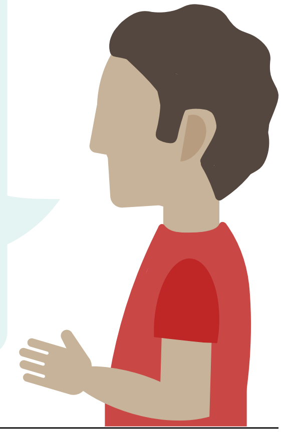
"Welcome and thank you for coming today. My name is __________ and these are my colleagues ______________ and ____________________. This focus group is being carried out for the Ryan White HIV Health Services Planning Council in ______________________, the group that makes decisions about how HIV/AIDS treatment funds are to be used. I am [Identify yourself and the other team members – e.g., a consultant helping the Planning Council with its annual needs assessment, a member of the Consumer Committee.] We are conducting this focus group as part of our information gathering for a needs assessment, to provide information the Council needs to make sound decisions about services and how available funding should be allocated – and especially about what we need to do to help people living with HIV enter and remain in care.

I will be leading today's discussion. My most important role is to ask questions, keep to the timeframe, and make sure that you all have the chance to share your knowledge and experiences. My colleague, __________ will help me with managing the discussion, and will also be taking notes. ____________ will be handling logistics and making sure you receive your reimbursements and gift cards. In addition we will be audio recording the session to ensure that we don't miss any of your answers. The discussion session today will take about two hours total, including a break."

2. Purpose of the focus group session

"As I mentioned earlier, the Planning Council is assessing service needs and barriers for people with HIV in the metropolitan area of __________________. The purpose of this focus group is to learn more about why people with HIV sometimes are not receiving regular HIV-related medical care and treatment. We know some of you are currently out of care, and others recently started receiving care.

We have asked you here to talk about your experiences with testing and care, including reasons you have been out of care and what factors have helped or might help you and other people like you get into care and stay in care."



3. Confidentiality

"All the information we collect here today is confidential. We will use the information you provide, but we will not identify any of you in anything we do related to this meeting. For example, we will not use your name, address, or any other identifying information in reports or other materials related to this focus group."

4. Consent forms and demographics questionnaire

"Before we begin the discussion, I would like you to review and sign the consent form given to you when you came in. The consent form will be our record that you agreed to participate in the focus group, you agree to the recording, and you understand that we will keep information confidential. We need a signed consent form from each participant.

The consent form also says that everyone in the room should respect confidentiality. If you know each other, we ask that you not talk about specific individuals and the information they shared. It is fine to talk about the discussion, but not to identify who said what.

Are there any questions about the consent form?

We would also like to collect the questionnaire that we asked you to complete when you arrived. The questionnaire will give us some information about your background. We will combine the information from all participants and use it to describe the whole group. We will never use any identifying information about you in our reports.

Are there any questions about the questionnaire?

Please pass your signed consent form and completed questionnaire to _________."

[Coordinator: Collect signed consent forms and completed questionnaires]

5. Reimbursement/Incentive

[Describe travel reimbursement and incentive arrangements; indicate that everyone will receive them at the end of the session.]

Focus Group Guidelines

"Let me begin our discussion by reviewing a few things about the focus group.

We will be focusing on some specific topics. We are interested in what everyone has to say about them. If someone throws out an idea that you want to expand on, or if you have a different point of view, please speak up. Sometimes I may have to interrupt the discussion to bring us back to the topic or to move on to another question or topic, to make sure that we cover everything on our agenda.

We will follow several practical guidelines during this session:

- We want everyone to express your opinions about the discussion topics. We are interested in different points of view. There are no right or wrong answers, and we are not here to resolve any issues you may bring up or to reach agreement. We just want to understand your views.
- Give us only your first name or a nickname. No one needs identifying information about you. If you know each other, we ask that you agree to keep information confidential – if you discuss the things people said here, do not identify the people who said them.
- Feel free to agree or disagree with what other people say, while respecting their views.
- Please do not hold side conversations. We want to be able to hear from everyone, and to be able to hear what everyone says.
- Please wait to be recognized by the moderator before speaking.
- Sometimes we will go around the table to share views on a topic. You can always "pass" if you prefer not to comment on that particular topic.
- Because we are also audio-recording the session, it would really help us if you could speak up.

Do you have any questions so far?"

Focus Group Discussion

[Note taker: Note start time and number of participants]

"Participant introductions: Now, let's go around the room and have each of you introduce yourselves; give your first name or a nickname, and tell us how long you have lived in this area, and how long you have been living with HIV.

Now let's talk more about your experiences with HIV medical care.

1. **What is your care status – are you currently receiving regular HIV-related medical care?**

   [Probes: Are you currently receiving HIV-related medical care? Are you on anti-retroviral drugs? If you are not currently in care, have you received HIV care in the past? If yes, when did you enter care? How long were you out of care? How long has it been since you entered or got back into care?]

2. **If you are now in care or have been in care, where have you received your HIV-related medical care? Where do you or did you go to receive care?**

   [Probes: At a clinic or health center? Which one? At an HIV clinic? From a private doctor?]

   Are you receiving or have you received other HIV-related services?

   [Probes: For example, have you received services like case management, or transportation assistance, oral health/dental, mental health, support groups, or substance use treatment? Food baskets or home-delivered meals? Emergency financial assistance? HIV-related housing assistance?]

3. **When you first found out you had HIV, what did you do?**

   [Probes: How did you react? How did you learn about the disease? Did you have someone who helped you deal with the diagnosis? Did another person with HIV give you advice?]"

4. **"Right after you were diagnosed, did someone at the testing place try to help you get linked to care?**

   [Probes: Where were you tested? Did someone associated with the testing site encourage you to go to a doctor immediately? What did they offer? What information did they provide? Did they provide a referral or offer to go with you to enroll? How helpful were they and why?]

5. **Did you try to get care right after you found out you have HIV, or did you wait? What did you do and why?** If you didn't immediately get care, tell us why. We'd like to understand your personal reasons.

   [Probes: For example, other health issues, or a difficult personal situation, or being in jail or in prison, worrying about stigma, or not feeling ready to deal with the disease?]

   We'd also like to understand program-related reasons – things about the clinic or system of care that made it hard to you.

   [Probes: Did you know that free or low-cost services were available if you couldn't pay? Did you know about the importance of taking antiretroviral medication as soon as possible, to stay healthy?

[Now or about halfway through your time period, give people a 10-minute break, to go to the restroom and to have some refreshments.]

6. **Some of you were in care, then dropped out – or have been in and out of care several times – or you may know other people who have had that experience. Why does this happen? What is the single most important reason you personally delayed entering care or dropped out of care?**

   [Probes: Did you have bad experiences at a service agency? What could be done to keep people from leaving care? How important are access issues, like transportation and hours of operation?]"

7. **How important is stigma or concern about having people know your HIV status – to what extent does it keep people out of care?**

   [Probes: Do you know people who don't seek care because of worries about having people know their HIV status? Would you hesitate to get care if it meant lots of people would know your HIV status?]

8. **At the time you were diagnosed with HIV, did you have a "medical home" – a regular doctor or a clinic where you received your medical care?**

   [Probes: Did you get regular physical examinations? Flu or other vaccines? Where did you go when you got sick – to a regular provider? An emergency room?]

9. **What leads people to come back into care? If you were out of care but recently returned to care, what led you to do that?**

   [Probes: Were you feeling sick? Did someone convince you to return to care? Did something important change in your life?]

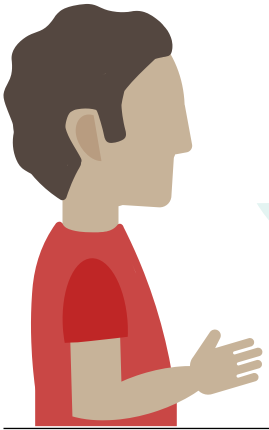
10. **What difference would it make to people who are newly diagnosed if there was a peer to help them get ready for HIV-related care and get medical care for the first time?** This would be a person with HIV who is receiving regular medical care – someone who could help you learn about available care, provide information about HIV disease, go with you to your first few appointments, and help you find your way through the care system.

11. **How useful would it be to have a peer who could help you stay in care or get back into care?**

    [Probes: Could a peer be helpful with improving adherence to medications? Making sure people get to their medical appointments, providing information and encouragement? Maybe doing with you to an appointment, or helping people fill out intake forms?]

12. **If you could make one change to make it easier for people to get into HIV-related medical care, what would you do?**

13. **Is there anything else we should understand in order to help ensure that people are tested for HIV and get into care as quickly as possible, and that they stay in care?**



Closing Remarks

"Thank you very much for participating in this focus group. The information you have provided has been very helpful. It will be used to help the Planning Council and Health Department make informed decisions about ways to help people with HIV get in care and stay in care.

Are there any questions that I can answer before we end the session?

Thank you again for your help. We really, really appreciate your time and your knowledge.

___________ will help you pick up your transportation reimbursement and gift card before you leave."