

*This document contains focus group scripts of three video vignettes on survey research, ethnographic research, and clinical research.

ATTACHMENT A – FACILITATOR’S GUIDE

PARTICIPANT PERSPECTIVES ON DRUG USE/HIV RESEARCH RISK

Phase I—Focus Groups

Facilitator’s Guide

Moderator Introduction. Thank you for coming today. I am Dr. Celia Fisher. I am at Professor at Fordham University. Adam and Matt are my colleagues and you all know Patrick. I have spent much of my professional life trying to make sure that researchers treat people they recruit with respect and protect them from harm. We’ve asked you here today to get your advice on how to improve the way research is conducted when it involves persons who use drugs and are at risk of HIV. I hope to make sure that your voices and opinions are heard by the National Institute on Drug Abuse, that is funding this study, and by other researchers across the country. We really appreciate your help and after the session Patrick will give each of you \$25 as well as a round trip Metrocard.

We are not going to ask you any personal questions during these discussions. We are going to show you 3 video clips with people who are acting out what happens in real life studies on drug use and HIV. All we are asking is for your opinions about the studies you watch.

We are audio taping the discussion to make sure we remember everything you say. But to make sure your privacy is protected we’ve asked you to wear these colored buttons. So even if you know each other, we are going to call each other only by our color names.

Let’s go around the table and I’d like to ask you to state your color name: And then also let the group know whether or not you’ve ever been in a research study and what you think about it. I’ll start for example, Hi I’m purple and I was once in a research study that asked me how I felt about people that don’t like me. And I didn’t like being in that study!!!

Go around table

Okay, now we are going to show you the first short video.

VIGNETTE 1 FOCUS GROUP PROBES SURVEY RESEARCH

In this video the researcher named Sara approaches John on the street and asks him to be in a study in which he will answer questions about his drug use and get tested for HIV. After the video I'd like us to talk about whether you think there are risks for John to agree to be in this study and what researchers could do to lower these risks.

1. If you were John would you agree to be in this study? Why/Why not
2. What do you see as the risks to John if he agrees to be in this study?
 - Are there any risks to being recruited on the street by Sara?
 - Are there any risks to John's friends or family or people he may do drugs with?
 - Do you think Sara will protect John's privacy?
 - What about the other researchers who will ask him questions and test him for HIV? Will they protect his privacy?
 - Is there anyway to lower these risks?
 - Are there any benefits of the research to John, the community, other drug users or people with HIV?
3. Do you think John was told enough about the study to agree to make an appointment to participate?
 - What if John was High, is it moral to ask him to be in the study?
 - What do you think about the fact that he won't be able to participate if he comes to the Center and is too high?
4. Do you think \$40 is a fair payment for John's participation?
 - Do you think that the offer of \$40 would be so much that the participant couldn't turn it down even if s/he didn't want to be in the study?
 - What if the researcher offered her/him \$100?
 - What if the participant was offered coupons for food or clothing?
 - Would this be any different if the participant had a steady job or was
 - Do you think researchers should give money to persons who use drugs who may use the money to purchase drugs?
5. Should John trust Sara? Why or why or not?
 - Are there any racial issues involved?
 - Do you think Sara is concerned about being fair, doing what is right? Why or why not?

VIGNETTE 2 FOCUS GROUP PROBES ETHNOGRAPHIC RESEARCH

The last video we are going to show you is about a researcher named Maria, who hangs out with drug users to learn more about their drug use and HIV risk behaviors. Steve is a drug user who has been in Maria's study and who helps her find other people to be in the study. As you will see, Maria has 2 dilemmas in this clip: whether to tell Steve's sexual partner that he is HIV+ and whether to give Steve money to help him get a fix.

1. Do you think the researcher should keep Steve's HIV a secret from Chris?
 - Does it matter that Maria told Steve when she first met him that she might have break confidentiality if she found out he might harm someone?
 - Do you think Steve thought Maria meant she would disclose his HIV status?
 - What if it was the other way around and Maria found out that Chris was HIV positive and Steve did not know?
2. Would it be any different if we were talking about someone who is HIV and sharing needles with people who are clean?
1. Suppose Maria was interviewing Steve's 12 year-old daughter and the daughter told Maria she was sexually involved with a man the researcher knew had HIV?

NOW LET'S TURN TO THE MONEY ISSUE:

2. Do you think Maria should give the money to Steve so he can buy drugs before she interviews him?
 - What do you think the consequences are for Maria if she gives Steve the money without finishing the interview?
 - Is it right to pay people if you know they are going to use the money for drugs?
3. Are Steve and Maria friends?
 - Should Steve trust Maria?
 - Should Maria trust Steve?
4. Do you think the study Maria is conducting will help Steve or his community?
5. Are there any other moral issues involved?

VIGNETTE 3 FOCUS GROUP PROBES CLINICAL RESEARCH

Now we are going to show you video about another type of research. In this study, the researcher Dr. Alva is asking Edward to be in a study that tests whether a new medication can help people get off addictions to cocaine. After you've seen the video clip I'd like to ask you questions about the risks and benefits to Edward of participating in the treatment study and whether you think Dr. Alva has explained the study well enough to Edward.

6. Do you think Edward should participate in this study? Why/not?
7. Do you think Edward understands that Dr. Alva does not know whether the new medicine can help people get off cocaine? Does s/he realize this is a test of the new drug?
 - Do you think it is fair to test the new drug with people like Edward?
 - What do you think about the use of a placebo in this study? Is it fair that some people will get the new drug and some people won't?
 - Do you think Dr. Alva has done all s/he can to help people who agree to be in the study?
 - What do you see as the risks for Edward if he agrees to be in this study?
 - What could Dr. Alva do to lower the risks?
 - What do you see as the benefits for Edward if he agrees to be in this study?
 - What could Dr. Alva do to increase the benefits?
3. Do you think Eva/Edward feels s/he has a choice about participating in the study?
 - Is providing the new medicine for free a good thing?
 - Does it force Edward to agree to be in the study because s/he can't afford to get his/her own treatment?
 - Are there things Dr. Alva could change to make sure Edward's choice is really voluntary?
 - Do you think /Edward should be paid for being in a treatment study? Why or why not? Is a treatment study different from other studies that participants would be paid for?
4. Should Eva/Edward trust Dr. Alva? Why or why or not?
 - Do you think Dr. Alva is concerned about being fair, doing what is right?
 - Does the type of drug Eva/Edward uses make a difference in your opinions?
 - Are there other moral issues raised by this study?