

“Understanding Barriers and Facilitators to HIV Prevention, Care, and Treatment”

2k. PLWH In-Depth Interview Guide English

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Understanding Barriers to HIV Treatment, Care and Prevention

PLWH

Interviewer's Protocol

Date_____

Interviewer ID_____

Interviewer Confirm You Have:

two consent forms

token of appreciation

receipt for token

two tested and working audio recorders

INTRODUCTION FOR RESPONDENT:

My name is _____ and I'm going to be your interviewer for the next hour or so. Thanks in advance for agreeing to do this study. I'm really looking forward to our conversation. Let's start out by telling you more about your participation in this research study and your privacy.

[HAND CONSENT FORM TO RESPONDENT]

This is a **consent form** that gives you details about your rights as a respondent in our study, and the steps that we will go through to make sure that your private information is protected.

[READ CONSENT FORM WITH RESPONDENT, DETERMINE IF HE HAS ANY QUESTIONS. ANSWER QUESTIONS HONESTLY, THEN ASK AGAIN UNTIL RESPONDENT HAS ALL QUESTIONS ANSWERED. IF RESPONDENT AGREES TO INTERVIEW HAVE RESPONDENT SIGN AND DATE FORM. PROVIDE A SECOND COPY TO THE RESPONDENT.]



[TURN ON AUDIO]

[READ] As you know, this interview is being audio recorded. Thank you again for being in our research study, which will help us understand why people living with HIV do or do not engage in medical care and treatment for their HIV. Funding for this study is provided by the Centers for Disease Control and Prevention (CDC). Please answer the questions honestly and to the best of your ability. **There are no right or wrong answers.** Remember that you can stop at any time you like or skip any question you prefer not to answer. We take your privacy very seriously. Your answers are completely private, and all personal identifying information – e.g. names of family members or partners – will be removed from the transcript. We encourage you to use nicknames or descriptors such as 'my daughter' when talking about other people or places, particularly if this makes you feel more comfortable. Please try not to use your own or other people's full names or identifying details.

SECTION A: BRIEF RESPONSE

INTERVIEWER READ INTRODUCTION: I am now going to ask you several quick questions to get a better background understanding of you and your situation. Please answer openly and to the best of your abilities. Remember that you can refuse or skip any question you don't wish to answer.

A1. How old are you?

- a. Under 18 years old → STOP INTERVIEW
- b. 18 - 25 years old
- c. 26 - 35 years old
- d. 36 years and over

A2. Do you think of yourself as:

- a. Gay
- b. Straight, that is, not gay
- c. Bisexual
- d. Something else
- e. Don't know/Questioning

A3. Do you consider yourself to be of Hispanic, Latino/a, or Spanish origin?

- a. YES
- b. NO
- c. REFUSED
- d. DON'T KNOW

A4. Which racial group or groups do you consider yourself to be in? You may choose more than one option.

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or Other Pacific Islander
- e. White
- f. REFUSED
- g. DON'T KNOW

A5. In what country or territory were you born? [DON'T READ CHOICES. CIRCLE ONE.]

- a. United States
- b. Other (Specify: _____)
- c. REFUSED
- d. DON'T KNOW

A6. What is the highest level of education you completed?

- a. Never attended school
- b. Grades 1 through 8
- c. Grades 9 through 11
- d. High School diploma or GED
- e. Some college, associate's degree, or technical degree
- f. Bachelor's Degree
- g. Any post-graduate studies
- H. REFUSED
- i. DON'T KNOW

A7. During the past 12 months, have you had any kind of health insurance or health coverage?

This includes Medicaid and Medicare.

- a. Yes
- b. No SKIP TO A9.A9.
- c. REFUSED
- D. DON'T KNOW

A8. During the past 12 months, was there a time that you didn't have any health insurance or health coverage?

- a. Yes
- b. No
- c. REFUSED
- D. DON'T KNOW

A9. Are you currently...?

- a. Employed for wages
- b. Self-employed
- c. Out of work for more than 1 year
- d. Out of work for less than 1 year
- e. A Homemaker
- f. A Student
- g. Retired
- h. Unable to work
- i. Something else (SPECIFY)
- J. REFUSED

- A10. In 2013, what was your total combined yearly household income from all sources before taxes? "Total combined household income" means the total amount of money from all people living in the household. *(INTERVIEWER: Clarify range if not clear in response)*
- a. \$ 0 to \$25,000
 - b. Over \$25,000 but under \$50,000
 - c. \$50,000 or over but under \$75,000
 - d. \$75,000 or over
 - E. REFUSED
 - F. DON'T KNOW
- A11. Do you currently receive any of form of public assistance?
- a. Yes -- What is it? _____
 - b. No
 - c. DON'T KNOW/ DON'T REMEMBER
- A12. [ASK FOR SPANISH ONLY] The rest of this interview is all in Spanish, but for classification purposes we need to ask: how well you speak English? Would you say...
- a. Very well
 - b. Well
 - c. Not well
 - d. Not at all
 - E. REFUSED
 - F. DON'T KNOW
- A13. In the past 12 months have you stayed on the street, in a shelter, or temporarily in someone's home because you had no regular place to live or stay?
- A. Yes
 - B. No
 - C. REFUSED
 - d. DON'T KNOW

A14. Who lives in your household? Please tell me by giving their relationship to you rather than their name like 'my grandmother' not her name. *[INTERVIEW: Note descriptors for use in IDI]*

DESCRIPTOR 1 _____

DESCRIPTOR 2 _____

DESCRIPTOR 3 _____

DESCRIPTOR 4 _____

ADDITIONAL DESCRIPTORS _____

COUNT _____

Section B: HIV EXPERIENCE AND HISTORY

INTERVIEWER READ:

Thank you. **This rest of the interview will be more like a conversation.** We would like to talk about your experiences and opinions on HIV treatment, care, and what influences your being or not being in care. Please be as open and honest as possible with your answers. We want to hear everything you have to say.

HIV & Testing History

GOAL: HIV When, where how re: status

B6. Tell me about your history with HIV.

GIVE THE RESPONDENT A CHANCE TO START TALKING. LISTEN ACTIVELY. ALLOW R TO CONTINUE FOR TOPICS COVERED IN THE INTERVIEW AND REFER TO IT DURING PROBES AND PROMPTS.

B7. Now thinking back, how did you first find out you were HIV positive? (*INTERVIEWER: where was test taken, was there a discussion with anyone, where did that happen*)

B8. What made you get tested that time; was it your decision or someone else's?

B9. Had you ever been tested before that?

- a. IF YES→Tell me more, when and how often? What were the results?
(*INTERVIEWER: check for patterns*)
- b. IF NO→Tell me more about that, had you thought about getting tested? (IF NECESSARY: What are some of the reasons you had not been tested before?)

INTERVIEWER CHECK: By the end of this section you should understand his first HIV+ testing experience, where it happened, what motivated the testing and if there is a history of any previous testing.

HIV & Relationships

GOAL: Social support, who has been told HIV+ and why

- A2. Some people talk to other people about their HIV status while others don't feel comfortable telling anyone. Tell me about your experience with talking about your HIV status with the people that you know, like your family or friends? *(INTERVIEWER: Give R a chance to discuss then use the following questions as probes below if not already answered)*
- A3. Who [else] have you been able to tell that you are HIV positive? *[INTERVIEWER: Remind R if necessary to use descriptors, never names]*
- A4. You said you told your [CLOSE RELATIONSHIP DESCRIPTOR TOLD]. Tell me about why you decided to tell them your status?
- A5. And what happened when you told him/her? That is, what was his/her reaction?
- A6. And what about the other people/[DESCRIPTOR]? What made you tell them your status?
- B10. And what happened when you told them? That is, what was their reaction(s)?
- B11. Did they react as you had thought they would?
- B12. Other than the person(s) you told me about, have you told other people too, like people in organizations you belong to? IF NECESSARY: For example your church or faith community, or at your job?
- B13. And now thinking about that same question, feeling comfortable or not comfortable, tell me about people you've chosen not to tell.
- B14. What are some of the reasons you do not tell people your status? Anything else?
- B15. And you mentioned you have not yet told your [CLOSEST RELATIONSHIP DESCRIPTOR NOT TOLD]. Tell me what you think his/her reaction would be if you told him/her? *(INTERVIEWER: repeat if necessary for second close relationship such as parent and partner)*
- B16. Other than the people we've talked about already, when have you told or not told your status to people you have had a sexual encounter with? Have you told all of them or not all of them? Why?

- B17. And thinking about sexual encounters with anyone, when do you and when don't you use protection? PROBE: What sorts of protection/prevention do you use? Is it different for those encounters with people who are HIV negative or unknown?

INTERVIEWER CHECK: This section is about Social Support. You should understand how supported R feels by others, who R feels comfortable telling his status to, if he chooses to tell or not tell based on how he thinks they will react, privacy, need to know or something else. And what kind of emotional and material/logistic support they provide R that can help their involvement in care. You should also know when he does and does not use protection with those he has told and not told.

SECTION C: HIV TREATMENT EXPERIENCE

DEFINING TREATMENT

- A7. Now I'd like to talk to you about HIV treatment and care. What does HIV treatment and care mean to you?

- C6. What kinds of treatment are available for HIV?

C6a Do you have all these treatment options available to you?

- C7. How important is it for someone to know lab values, like how much virus is in the blood, if they are living with HIV? Why is that important? Tell me more

- C8. How important is it to see a doctor or nurse regularly if a person is living with HIV? Why is that?

INTERVIEWER CHECK: You should understand how the R defines treatment/care and its importance

HIV TREATMENT CONTINUUM

- C9. Now I'd like to talk about your own HIV treatment and care. Tell me about your HIV treatment and care plan if you have one? IF NECESSARY: Are you currently on any antiretroviral medicine/meds, some people call it ARV therapy?

- C10. About how often are you asked to schedule an appointment to see a doctor or nurse about your HIV care? How often do you see a doctor or nurse? When was the last time?

INTERVIEWER CHECK:

If R is currently taking ARV medications then continue to Section D: below,
If R is not taking medications skip to

SECTION D: CURRENTLY IN TREATMENT

Interviewer Note: Some of these questions may have already been answered, verify and skip those you are sure have been answered.

CONTINUITY

D6. So we've talked a little bit about what HIV treatment means to you and you also said you are currently taking meds for your HIV. Tell me more about your experience with taking HIV meds and the care you've received.

D7. How old were you when you were diagnosed with HIV? How long have you been living with HIV? Have you been in treatment and care for HIV the whole time or just some of the time? (*Interviewer: Probe to clarify anything other than the whole time for length of time off, how many times off, why he went off. If stayed on the whole time, how, why, what facilitated continual care.*)

INTERVIEWER CHECK: You should understand if the R has been in continuous treatment, the facilitators for that continuity. If there are multiple breaks in ARVT, what are the length of breaks from ARVT, and why.

PROVIDER VISITS

D8. Thinking about your last five times you had a visit scheduled with your doctor or nurse for your HIV care, did you miss any of those visits? (*Interviewer: Probe for reasons*)

D9. And tell me more about how easy or hard is it to make those visits? [IF NECESSARY: Can you have them scheduled at times that work well for you or is it hard to find a time that works for you?]

D10. Is the doctor/nurse close by? That is, are you able to get to your appointments easily? IF NECESSARY: What would make it easier to make your appointments?

D11. How well do you understand what the doctor has to say?

D12. And how well does the doctor understand what you have to say?

D13. IN SPANISH ONLY: Is language a problem?

INTERVIEWER CHECK: You should understand R's current relationship with provider and visits and follow through of checkups. You should understand if R has been a no show for appointments and the barriers and facilitators to making those appointments.

ARVs

- D14. Tell me a bit more about the meds you are taking? What are they? Do you think they are working for you?
- D15. How about side effects? Do you have any with these meds or have you had some in the past? (IF NECESSARY: By Side effects I mean do the pills make you feel bad or have some other unwanted effect)
- D16. Do you have any other issues with taking your meds? Like trouble swallowing pills or do you not have any concerns with taking them?
- D17. Do you always take all your meds exactly like it says to on the bottle or pill box, the number and time and such? (*Interviewer, Probe for reasons why or why not*)
- D18. When was the last time your doctor or nurse asked you questions like this about your meds?

INTERVIEWER CHECK: You should understand any issues R has with ARVT and compliance

GENERAL HEALTH

ASK GENERAL HEALTH QUESTIONS BELOW ONLY IF R HAS MENTIONED CHRONIC HEALTH ISSUES

- D19. And what about any other health problems? Have you been told you have any other health issues? IF NECESSARY: Such as high sugar, weight, high blood pressure?
- D20. IF YES→ Do you take any medicines for that/those condition(s)? What else do you do to help with that/those condition(s)?

INTERVIEWER CHECK: You should understand if R has other medical issues that affect his HIV care and treatment and if they are treated

TREATMENT EXPERIENCE AND CONTINUUM

GOAL: Barriers and Facilitators

- D21. We've talked a little bit about your history taking HIV meds and seeing your doctor/nurse for HIV treatment but I'd like to spend a little more time on this. Have you always taken the same meds the same way as you do now or have things changed? How?
- D22. And what about your doctor/nurse, have you seen anyone else in the past?
- a. IF YES→ Tell me about them. What did you like or not like about where you went before?
- D23. What do you like about where you go now?
D18a What do you not like about where you go now?
- D19. Tell me a few things **you do** that help you stick with your meds and visits?
- D20. Are there other things that make it easy to stick with your meds? IF NECESSARY Like things the doctor/nurse/clinic does or family or anyone else?
- D21. And what about things that make it hard to stay on your meds?
- D22. What about things that make it hard to keep your doctor/nurse visits? [IF NECESSARY: Any others? Any people? What about things like transportation or travel or convenience?]

INTERVIEWER: IF NEVER OFF MEDICATIONS (Q. D7.) ASK D23. OTHERWISE SKIP TO D24.D24.

- D23. Has there ever been any time when you took a break from seeing your doctors/nurses or taking your pills? (IF NEVER STOPPED, SKIP TO SECTION F)
- D24. Tell me more about that time/those times when you were not taking the meds. PROBE FOR PERIOD(S) OF STOPPING/STARTING.
- D25. What (else) was going on in your life at that time? What were some of the reasons you did not take HIV meds in that period?
- D26. Did you and your doctor/nurse talk about your meds then? What happened?

- D27. You are now engaged in treatment and taking your meds. Looking back, is there something that could have helped you stay in care at that time/those times? Tell me more.

INTERVIEWER CHECK: End of section: You should understand barriers and facilitators to treatment and continuity of treatment.

GO TO SECTION F

Section E: Not Currently in Treatment

GOAL: Barriers to treatment

- E1. Now I'd like to talk a little bit about why you are not currently taking meds for HIV. Can you tell me a little bit about that? *INTERVIEWER NOTE: IF R uses alternative medications rather than ARVs probe on the reasons and switch wording of the remainder of the questions in this section to questions to 'antiretroviral meds'*
- E2. Have you taken meds for HIV in the past? Tell me more?
- E2a IF NECESSARY: What meds? Side effects? Life during that time? What changed?
- E3. .IF NO: Have you ever seen a doctor or nurse to talk about taking meds for your HIV? How did that visit go? What happened then?
- IF SEEN HCP: How well did you understand what the doctor had to say?
 - IF SEEN HCP: And how well did the doctor understand what you had to say?
 - IF SEEN HCP IN SPANISH ONLY: Was language a problem?
- E4. Do you think HIV meds would help you or not help you? Why is that?
- E5. IF NOT ANSWERED: Are there things that worry you about taking meds for HIV? Tell me about that.
- E6. Are there other reasons as well for not being in treatment?
- IF NECESSARY: What about cost? What about your state of mind? Feelings about the doctor or nurse who sees you? Any others?

- E7. Sometimes other health or wellness conditions affect someone's decision to take HIV meds. Do you have any other health problems? IF NECESSARY: Such as high sugar, weight, high blood pressure?
- E8. IF YES→ Do you take any meds for that/those condition(s)? What else do you do to help with that/those condition(s)?
- E9. And other than those meds, do you sometimes drink alcohol or take other drugs, things like marijuana, poppers, cocaine, or others?
a. IF NECESSARY: how does this impact your thinking about HIV pills?
- E10. What do you think would need to change for you to start taking meds for HIV?

INTERVIEWER CHECK: You should understand why they are not currently taking AVRT and what factors contribute to that situation.

***IF THEY HAVE NEVER TAKEN AVRT (Q.E2) THEN SKIP TO SECTION F
OTHERWISE CONTINUE BELOW***

Note to verify and confirm responses already discussed.

- E11. Just so I get a clear picture, tell me more about any times when you were taking HIV meds? PROBE FOR STOPPING/STARTING TO COVER ALL PERIODS OF MEDS.
- E12. What made you decide to stop that time/those times?
- E13. What might have helped you stay on your meds that time/those times?
- E14. When you were on the HIV meds, tell me about regular visits to see a doctor or nurse? How often they took place and what were they like?
- E15. How well did you understand what the doctor had to say?
- E16. And how well did the doctor understand what you had to say?
- E17. IN SPANISH ONLY: Was language a problem?

- E18. Did you have any problems getting to the visit or getting in to see your doctor/nurse?
- E19. Tell me about the meds you took then?
- E20. Did you feel those meds worked for you?
- E21. Did you have any problems taking them?
- E22. When you were taking meds for HIV, what were some of the hardest things about that, what did you NOT like?
- E23. And when you were taking meds for HIV, what things did you like, what worked for you?
- E24. Just so I understand, thinking about when you started taking meds for HIV to when you stopped taking meds, what had changed for you?

INTERVIEWER CHECK: You should understand the factors that led them to stop taking ARVT. Were the factors related to the ARV, to the health care setting, to their own condition or to economic or social factors.

CONTINUE TO SECTION F.

Section F: HIV LABS

GOAL: Understands lab values and own status

- F1. Now I'd like to talk to you a bit about how people think about their HIV. Do you know what your CD4 count is? Tell me about it.
- F2. What does that number mean to you? What is a CD4 count? *(Interviewer: If DK, have they heard the term? If not skip F3.)*
- F3. Has your CD4 count changed over time?
- F4. What is your viral load? What does that number mean to you? When was that measured? *((INTERVIEWER IF NECESSARY PROBE TO DETERMINE IF THEY HAVE EVER HEARD THE TERM IF NEVER HEARD SKIP TO SECTION G)*
- F5. Has your viral load changed over time?
- F6. Have you heard the term undetectable as it relates to viral load? What does it mean to you?
- F7. *IF VOLUNTEERED UNDETECTABLE: IF NECESSARY:* When were you told, how long ago?
- a. IF UNDETECTABLE: Tell me about what worked for you, like what meds you were taking and visits you were making to doctor/nurse ?
- F8. SKIP IF UNDETECTABLE - Have you ever been told your viral load is undetectable?
- a. IF YES→How long were you undetectable?
 - b. IF YES→How long did it take for you to get to that point?
 - c. IF YES →Tell me about why it changed back to detectable? What were the reasons?

INTERVIEWER CHECK: You should understand the extent to which the R understands the terms CD4 and Viral load, how aware he is of his own values and how much those numbers mean to him in terms of his health and if he has had success with ARVT in the past or currently.

Section G: Other Factors

GOAL: Cultural and other impact

We have talked a bit already about the doctors and nurses you have seen for your HIV care and where you go, but I'd like to just make sure I have a full picture.

- G1. Tell me some of the things you have liked when you think about the health care settings you have been to. The doctors, the nurses, the staff, the clinic setting such as waiting room - what works well for you?
- G2. What about things you have not liked?
- G3. How comfortable are you going to and being in the clinic or doctor's offices? IF NECESSARY: What about the neighborhoods they are in? Travelling to them?
- G4. What about (other) cultural issues? Do you feel your background or race have an impact on the care you receive/would receive?
- G5. What else would help you stay in HIV treatment and care?

INTERVIEWER CHECK: You should understand their experience with treatment providers and if cultural factors have impacted them.

REFERRED TO OTHER SERVICES

- G6. Finally I'd like to spend a couple minutes talking about other services that are sometimes suggested to people who are living with HIV. Have you ever been referred to other services, such as for diet, education or other ways to stay healthy?
 - a. IF YES: Who referred you
 - b. IF YES: Did you use the services? Tell me about that? Were they helpful?
 - c. IF YES: What could have made them better?
- G7. What about services like getting assistance for food, employment or housing?
 - a. IF YES: Who referred you
 - b. IF YES: Did you use the services? Tell me about that? Were they helpful?
 - c. IF YES: What could have made them better?
- G8. What about other services like mental health or drug or alcohol counseling?

- a. IF YES: Who referred you
- b. IF YES: Did you use the services? Tell me about that? Were they helpful?
- c. IF YES: What could have made them better?

G9. What about any other kinds of services? Like community support groups?

- a. IF YES: Who referred you
- b. IF YES: Did you use the services? Tell me about that? Were they helpful?
- c. IF YES: What could have made them better?

G10. What about any other kinds of medical services such as for your heart or other sexually transmitted diseases?

- a. IF YES: Who referred you
- b. IF YES: Did you use the services? Tell me about that? Were they helpful?
- c. IF YES: What could have made them better?

G11. Have you ever asked for help with any of the things I just mentioned? What happened?

G12. Do you think any of the services I just mentioned and that you haven't used might be helpful for you? Which ones?

G13. Do you think if someone had talked to you about any of these, you would have used them?

INTERVIEWER CHECK: You should understand if he has been offered services and if not, why not. If he has been offered services, has he taken advantage of those services and if not why not.

Section H: Closing

- H1. That is almost all the questions I have. Thinking about all the things we just discussed. What else do you think is important for me to know?
- H2. Are there any questions that I should have asked and didn't? What?

I want to thank you so much for your time and help today! That is all the questions I have.



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