

Form Approved

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**Surveillance of HIV-related service barriers among Individuals
with Early or Late HIV Diagnoses (SHIELD)**

Attachment 6C

In-Depth Interview Guide (English)

Public reporting burden of this collection of information is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. 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 CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; Attn: OMB-PRA (0920-1402)

SHIELD Qualitative Formative Supplemental Project

In-Depth Interview Guide (IDI)

This is a sample interview guide. The interview is expected to last between 60-90 minutes, during which time approximately 30 core questions will be asked to respondents. Potential probe(s), introductory and transitional statements are included in the sample interview guide. These questions may be modified as appropriate based on the responses provided by respondents.

Overall SHIELD Study Aim: To understand barriers, gaps, and failures in HIV prevention and testing services and systems that allow people to become infected (Stage 0) and receive a late diagnosis (Stage 3)

SHIELD Qualitative Interview Objectives:

- Identify novel structural barriers to HIV testing, prevention, and PrEP or PEP utilization for Stage 0 and Stage 3 individuals
- Understand the sociocultural context surrounding HIV prevention behaviors with partners, attitudes towards HIV Testing, and PrEP and PEP knowledge and acceptability among Stage 0 and Stage 3 individuals
- Identify novel prevention strategies for people at risk for HIV

Introduction

Hello, my name is _____. You were chosen for this interview because of your recent experiences related to HIV testing and diagnosis. No personal information, such as your name, will be written down or recorded.

The [State or Local Department of Health] and the Centers for Disease Control and Prevention (CDC) are interested in understanding your experiences to learn more about people living with HIV, including the services they use and need. Ultimately, your answers will help to improve HIV prevention and treatment services in your state.

Everything we discuss will remain confidential between you, me, and the people working on this project and your answers won't be linked back to you. You do not have to participate, and you have the right to refuse to answer any question. We will not be asking for your name. No personal information will be collected or linked to you.

Our conversation will take about an hour to an hour and a half, and to thank you for your time, we will give you a **\$50 Amazon gift code** at the end of the interview. You can stop me at any time if you have a question or concern, or if you want to skip a question or end the conversation.

Does this sound like something you'd be interested in?

Great! Before I begin I want to go over a couple of items:

- With your permission, I would like to audio record our conversation. Maintaining your privacy is very important to us.- I do this simply to make sure that I capture all the information that you share and so I can listen to what you have to say and not worry about taking exact notes. The recording helps my team in writing a report. The audio file from this interview will be destroyed after the project ends. Again, I will not ask your name at any time. Is it okay for me to audio record our conversation? And if, at any point during our conversation, you would like me to stop recording, please let me know. We will also take notes (in case the recording does not work).
- So, before we get started, I just want to say there are no right or wrong answers. I am interested in your story. I understand that a new diagnosis of HIV can be emotional. If a question makes you feel uncomfortable we can skip it. You are also free to stop the interview at any time. Also, if you like, we can provide you with additional resources in your area for support and health care services.
- At the end of this interview, we will ask if you'd like to take a follow-up survey. This survey will take no more than 50 minutes and you will receive an additional **\$50 Amazon gift code** for your time. You can take this survey either over the phone or online.

Are you ready to begin?

Great! I will start the recording now.

To be completed by the interviewer at the beginning of the interview for eligible participants:	
Survey ID	
Type of Interview (check)	<input type="checkbox"/> Stage 0 <input type="checkbox"/> Stage 3 <input type="checkbox"/> Other (please specify) _____
Date of interview	
Site of interview	
Lead interviewer name	
Notetaker name	
If the participant does not wish to participate, note the reason(s) for refusal	
Interviewer Post-Interview Comments and Observations:	

Warm-up Questions

1. Tell me what you like or dislike about living in your city?

Probe(s):

How has [STATE/CITY] changed since you've been living there?

2. Describe where you've slept most nights in the last 30 nights?
 - *If the participant is struggling to answer this question, provide some of the following options as an example: your own house or apartment, a friend's place, hotel/motel, family house, car, street/tents.*

Health care beliefs and experiences

I'm going to start by asking you about your beliefs and experiences with health care before you received your diagnosis.

3. Can you tell me about your last experience visiting a health care provider before your HIV diagnosis? By health-care provider, I mean doctor, nurse, or other health care professional.

Probe(s):

- What was your reason for visiting the health-care provider?
- When was the last time you went to visit a health-care provider?
- Prior to your diagnosis, how often did you see a doctor?
- How did you feel about going to see a health care provider for care?

4. Was this a normal experience you had with health-care providers?

Probe(s):

- How did you normally feel during visits with health-care providers?

5. In general, what types of conversations did you have with your doctor about HIV before your diagnosis?

Probe(s):

- *(If they had a conversation about HIV)* Tell me about conversations you had with your health-care provider about HIV. What did you talk about?
- *(If they had a conversation about HIV)* Who brought up HIV, you or the provider?
- *(If they had a conversation about HIV)* What was that conversation like?
- *(If they had a conversation about HIV)* How did you feel during that conversation?

General HIV Questions

Next, I'm going to ask you some questions about your thoughts on HIV before you received your diagnosis.

6. What did you think about HIV before your diagnosis?

7. Where did you get information about HIV?

Probe(s): (If they had **no knowledge** about HIV):

- Where did you get information about health topics?
- What would have helped you learn more about HIV?

8. How did you think people around you (family, friends, co-workers) feel about HIV?

Probe(s):

- What conversations about HIV did you have with the people around you?
- (If yes to conversations with people in their network)
Did anyone you know ever say something judgmental or negative about people with HIV? If so, what did they say?
- (If yes to conversations with people in their network)
What were your feelings during these conversations about people with HIV?

Sexual Partners and Communication

Next, I'm going to ask you some questions about your sexual history in the 12 months before your diagnosis and the types of conversations you had with your sex partners about HIV before you received your diagnosis.

9. In the 12 months before your diagnosis, about how many people did you have sex with?

10. How would you describe your relationship with these people? Are they friendships, romantic relationships, or casual relationships?

- *If respondent has less than 10 partners, ask about each partner.*
- *If respondent has more than 10 sex partners, ask them to describe in general the type of relationships they had with their sex partners and an estimated number for each type of relationship*

11. How did you meet these people?

- *If respondent has less than 10 partners, ask about each partner (through friends, work, phone apps, etc.)?*
- *If respondent has over 10 sex partners do NOT ask about each sex partner, In general, how do you meet your partners (through friends, work, phone apps, etc.?)*

12. Sometimes people have conversations with their sex partners about STDs and HIV. What conversations about HIV did you have with your sex partners, if any?

(If yes to conversations about HIV, continue to question 13 and skip question 14)

(If no to conversations about HIV, go to question 14)

13. How were the conversations different depending on the type of relationship you had with that person?

Probe(s):

- When did you have these conversations with your partners, before or after sex?
- Who brought up the conversation?
- What was their initial reaction to the conversation? What was your reaction?
- Did you have these conversations with all your sex partners?

14. What are some reasons you didn't talk about HIV with your partner(s)?

PrEP

Next, I'm going to ask you some questions about your thoughts and experiences with pre-exposure prophylaxis, also called PrEP, before you received your diagnosis. PrEP is a pill that people can take every day to help prevent them from becoming infected if exposed to the virus.

15. What had you heard about PrEP before your HIV diagnosis?

Probe(s):

(If the participant has heard of PrEP)

- How did you hear about PrEP?
- How did you feel about PrEP before your HIV diagnosis?
- What are your experiences using PrEP before your diagnosis?

16. Have you ever taken PrEP?

Ask Questions 17-24 if respondent answers yes to Question 16.

Skip to Question 25, if respondent answers no to Question 16.

Questions for respondents that used PrEP:

17. How often do/did you take PrEP?
18. What were your experiences taking PrEP?
19. How did you make the decision to stop taking PrEP?
20. Who helped you make that decision, if anyone?
21. How did you feel about taking a pill every day?
22. What, if anything, would have helped you to keep taking PrEP?
23. (If never used PrEP AND had heard about PrEP) Did you know where to get PrEP?
24. (If participant never used PrEP AND had heard about PrEP) Why did you feel that PrEP was not right for you?

HIV Testing

Now, I'm going to ask you some questions about your thoughts and experiences with HIV testing before you received your diagnosis.

25. In general, how did you feel about getting tested for HIV before your diagnosis?

Probe(s):

- How often did you get tested for HIV?

26. What led you to get tested for HIV?

Probe(s):

- *Stage 0 participants only*, what led you to get tested more than once in the past 6 months?
 - o How often do you usually get tested? Do you often get tested every 6 months?
- *Stage 3 participants only*, have you ever been tested for HIV before your diagnosis?
 - o *If yes*, when was the last time you were tested?
 - o *If no*, what prevented you from getting tested for HIV?

27. (If tested for HIV before diagnosis) Tell me about your experience getting tested for HIV.

Probe(s):

- How was it getting to the location where you got HIV testing?

- Was there anything about your experience that would have discouraged you from getting tested again?

28. What had you heard about HIV self-testing before your HIV diagnosis?

Probe(s):

- *(If they know about HIV self-testing)* Did you ever use HIV self-testing?
 - o What do you think about self-testing?
- *(If they used HIV self-testing)* What was your experience using it?

Recommendations

I would like to know what some of your suggestions are to improve HIV testing and prevention.

29. What do you think could be done to get people to get tested for HIV?
30. What do you feel is the best way to get people hearing about PrEP?
31. What do you feel is the best way to get people to consider taking PrEP?
32. What needs to be done to prevent people from getting HIV?

Demographics

Before we end, I would like to collect some basic information from you about your characteristics.

33. What is your race?
34. What is your ethnicity?
35. How old are you?
36. What is your sex (do you identify as male or female?)
37. How would you describe your sexual orientation?

Closing Question

We are coming to the end of the interview. Just one more question...

38. The main goal of this project is to understand more information about experiences related to HIV testing and diagnosis. Is there anything else that we haven't discussed already that you want to share with me?