

Expanding PrEP in Communities of Color (EPICC+)

**Attachment 4m
Aim 2a Cohort Exit Interview Guide English**

Public reporting burden of this collection of information is estimated to average 60 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-New)

Cohort Exit Interview Guide

Questions will focus on understanding factors that influenced participants' selection of PrEP regimens, changes and/or discontinuations as well as perceptions of the counseling they received by providers at PrEP initiation and follow-up, receipt of tools or materials that influenced choice and feasibility/acceptability of the EPICC+ app.

Introduction

Read: My name is ---. My pronouns are ---. Thank you again for agreeing to participate in this interview today. The purpose of our discussion is to better understand your decisions around PrEP use, how you felt about the counselling you received from you PrEP provider, and get your feedback on the EPICC+ app.

- Today I want to learn about your experience and your thoughts in your own words. It's your story and you are the expert. I'm here to learn from you. There are no right or wrong answers. All of your feedback and ideas will be helpful to us in making the app better. And, you don't have to worry about offending me – please feel free to speak your mind.
- As a reminder, your participation is voluntary. If there are any questions that you prefer not to answer, please tell me, and I'll move on to the next question.
- The information you provide will be kept confidential. The responses of everyone I speak with will be reported as a group. Any direct quotes used as examples will not include your name or any other details that could be used to identify you.
- I want to make it clear that giving your honest answers to my questions will not affect your treatment at the clinic in any way. The staff at [insert clinic name] want to improve their patients' experiences. By agreeing to talk to me, you are providing useful information that will improve all patients' care.
- To protect your privacy, it is important that you stay in a room alone so that no one hears you sharing any information or knows whether you are participating in this study. Can you do that right now? [IF YES, PROCEED, IF NO, STOP AND RESCHEDULE INTERVIEW]
- We would like to record the interview today. The recording will ensure that our notes of today's conversation are complete and accurate. We will destroy the recording at the end of the study.
- If you need to use the restroom or step away for a moment, please let me know. We can pause the interview and restart when you return.
- Do you have any questions? If not, great. I am starting the recording now. TURN ON TAPE RECORDERS AND SAY: Now that I have the recorders on, may I have your verbal permission to record our interview?

PrEP Background and PrEP Choice

It's helpful if you tell me a little bit about your experiences taking PrEP, so to start...

1. Are you currently on PrEP?
If yes:

- a. What type of PrEP are you on now? Daily oral, 2-1-1 or on demand, or injectable PrEP (CAB-LA)
- b. What prompted you to start taking (insert type of PrEP here)?
- c. There is a lot to consider when starting a new medication. Some people find it helpful to discuss things their partner, friends, family, or healthcare providers. Did you discuss taking [insert type of PrEP] with anyone in your life?
 - i. **If yes:** Did they do or say anything that helped you to make your decision?
- d. What factors, if any, influenced your choice? (examples could include but are not limited to: costs, side effects, availability, dosing schedules, etc.)
- e. Sometimes it can be difficult to start and continue new medications. People may encounter problems with remembering when to take their medication, medication side effects, medication costs, making or finding the time for appointments with their provider, or refilling their medications. Tell me about some of the challenges you experienced with the PrEP you are on (examples could include but are not limited to: costs, side effects, availability, dosing schedules, etc.)
 - i. **If challenges noted:** How have you dealt with these challenges?
- f. Have you ever been on any other types of PrEP?

If yes: ask previous questions starting with what type of PrEP were you on.

- g. Why did you decide to change the type of PrEP you were taking?

If no to currently on PrEP:

2. Have you ever been on PrEP in the past? Daily oral, 2-1-1 or on demand, or injectable PrEP (CAB- LA)

If yes:

- a. What type of PrEP were you on?
 - b. When did you start taking (insert type of PrEP here)?
 - c. What prompted you to start taking (insert type of PrEP here)?
 - d. There is a lot to consider when starting a new medication. Some people find it helpful to discuss things their partner, friends, family, or healthcare providers. Did you discuss taking [insert type of PrEP] with anyone in your life?
 - i. **If yes:** Did they do or say anything that helped you to make your decision?
 - e. What factors, if any, influenced your choice? (examples could include but are not limited to: costs, side effects, availability, dosing schedules, etc.)
 - f. Sometimes it can be difficult to start and continue new medications. People may encounter problems with remembering when to take their medication, medication side effects, medication costs, making or finding the time for appointments with their provider, or refilling their medications. Tell me about some of the challenges you experienced with the PrEP you **were** on in the past (examples could include but are not limited to: costs, side effects, availability, dosing schedules, etc.)
 - i. **If challenges noted:** How did you deal with these challenges?
 - g. Why did you decide to stop (insert type of here)?
3. What do you think about (insert PrEP option that participant has not been on)?

If the participant has not heard of injectable PrEP "Injectable PrEP is a different kind of PrEP dosing strategy where instead of taking an oral pill, you get an injection every two months."

If the participant has not heard of on-demand PrEP: *“On-demand, or intermittent/event-driven PrEP, is a different kind of PrEP dosing strategy where instead of taking a daily pill, you take a series of four pills only if you plan on having sex. Known as the “2-1-1” schedule, on-demand PrEP requires the individual to take two pills 2-24 hours before they have sex, one pill 24 hours after the first dose, and one pill 24 hours after the second dose.”*

Relationship with PrEP Provider

Now that we know a bit about your experience taking PrEP, we'd like to discuss your relationship with your PrEP provider.

4. How would you describe your relationship with your provider?
5. Tell me about any discussions you had with your provider that helped you to successfully stick to your PrEP treatment.

Can remember helpful discussions:

- a. What did you talk about?
- b. What did your provider say or do that was helpful?

Can't remember helpful discussions:

- c. What things about starting and sticking with PrEP would have been helpful to know or talk about with your provider?
6. What else did you discuss with your provider? (Probe for discussions on choosing PrEP type, changes to PrEP, etc.)
 - a. **If challenge with PrEP was noted earlier:** Earlier, we talked about some of the challenges people face when beginning a new medication. Did you discuss [insert PrEP challenge here] with your provider?
 - i. How did your [insert challenge here] come up during the appointment?
 - ii. How did your provider address your [insert challenge here] during the appointment? Probe for suggestions offered, materials, etc.
 - iii. Did this discussion help you address [insert challenge here].
 - b. **If participant did not note PrEP challenge earlier:** Tell me about a time when you and your provider discussed some of the challenges, you might encounter when taking [insert type of PrEP here].
 - i. What did you discuss?
 - ii. What was most helpful about this discussion?
 - iii. What was least helpful about this discussion?
 - iv. Did the discussion help you to overcome any problems with continuing your treatment plan?
7. Were there any topics you would have liked to discuss with your provider that were not discussed?
 - a. **If yes:** Why didn't you bring this topic up during one your appointments?
8. Did you feel that your provider listened to you and understood what was important to you in terms of your PrEP treatment?
 - a. Can you tell me more about that?
9. During discussions with your provider, did they ever provide you with any tools or materials related to PrEP? (Examples could include but are not limited to PrEP brochure, adherence tools, etc.)

If yes:

 - a. What did you think about these materials?
 - b. How, if at all, were the materials helpful?

- c. How could they be improved?
 - d. What types of materials do you think could help you and other people on PrEP?
- 10. Do you feel that your PrEP provider is aware of and understands the health needs and challenges that young, ethnically diverse, gay men in the [city name] community face? Why or Why not? Give me some examples.
- 11. How could discussions with your provider be improved?

Clinic Staff and Services

Now we'd like to briefly talk about other clinic staff members and clinic services.

- 12. Besides your PrEP provider, were there any other staff members you discussed PrEP with at [insert name of clinic]?

If yes:

- a. What was the staff member's role in the clinic? (PrEP navigator, pharmacist, nurse, etc.)
 - b. What did you discuss?
 - c. What was most helpful about this discussion?
 - d. What was least helpful about this discussion?
 - e. Did the discussion help you to overcome any problems with continuing to take PrEP?
- 13. What do you like best about the clinic? (examples could include: appointment setting, scheduling/clinic hours, transportation, parking, office staff, teamwork, wait-time, pharmacy, lab, billing, staff interactions/behavior, treatment, and follow-up communication)
- 14. What could the clinic improve on? (examples could include: appointment setting, scheduling/clinic hours, transportation, parking, office staff, teamwork, wait-time, pharmacy, lab, billing, staff interactions/behavior, treatment, and follow-up communication)
- 15. Would you recommend the clinic to other people who are interested in starting PrEP? Why or Why not?

Overall App Satisfaction

- 16. Could you talk a little bit about your overall impression of the app?
 - a. What did you like most? Least?
 - b. What was most useful? Least useful?
- 17. How did you use the app during your time in the study?
 - a. What parts of the app did you use most? [Display a PowerPoint that includes screenshots of the different features in the app.]
 - i. Probe specifically on medication tracker – did they use, how often, why/why not
 - 1. If used- probe how/how didn't impact adherence to PrEP
 - ii. Probe specifically on sex diary- did they use, how often, why/why not
 - 1. If used- probe how/how didn't impacted sexual behaviors
 - iii. Ask about any other areas of app used
 - 1. Probe how impacted their PrEP use
- 18. How did the way you used the app change from when you first started until now?
 - a. Probe specifically on medication tracker and sex diary

Perceived Impact of EPICC+

- 19. How has using the app impacted the way you think about things in your daily life?
 - a. Can you provide a specific example? (probe for health, relationships, other areas)
 - i. What things have you done differently as a result?
- 20. Did you feel like the app was well-designed for you? Why/why not?

21. Would you feel comfortable referring friends or members of your network to use the app? [probe for why/why not.]
22. If this app was publicly available, what parts do you think you would keep using, if any?
23. What would make you use the app more?
24. What other functions or features would you like the app to have?

EPICC+ Functionality and Technical Performance

25. What parts of the app did you find easiest to use?
26. What parts were most difficult to use?
27. Could you describe any technical problems you had?
28. Do you have any recommendations for how we could improve the app?

Blood Testing

29. Did you complete any blood collection kits during the study?
 - a. **If no:**
 - i. What kept you from completing the blood collection kits?
 - ii. What would have motivated/helped you use the blood collection kits?
 - b. **If yes:** [Display a PowerPoint that includes screenshots of the steps for completing blood collection.]
 - i. What was your experience like ordering and receiving the blood collection kits?
 - ii. What was your experience like using the blood collection kits?
 - iii. What were the most difficult parts of completing the test?
 - iv. How would you feel about using the blood collection kit as part of your regular care for checking your PrEP protection in-between clinic visits?
 - v. What would you change about the blood collection kits to make them better or easier to use?

WRAP UP

What other ideas or feedback do you think we should talk about related to the app or the study that we haven't talked about yet today?

Those are all the questions I have today. Do you have any questions for me?

Great. Someone from the study team will contact you shortly about sending your incentive.

Thank you again so much for taking part in this study and in this interview. Your experiences and perspectives are very important to us and helpful in improving the app!

If this interview made you feel uneasy or you have concerns about anything we discussed, please contact the EPICC staff for support using one of the following methods:

- Call or text the EPICC study phone number at (448) 488-9069
- Use the in-app messaging feature
- Use the Ask the Expert feature
- Send an email to EPICC@nursing.fsu.edu

You can also leverage the EPICC community in the forum or use the Care Locator tool to find services in your area.

Lastly, there are many resources available through national organizations such as:
[Include the following information on a PowerPoint]

The National Suicide Prevention Lifeline – Participants can now dial **988** to access mental health crisis services.



Trevor Project – Participants can reach out to a counselor, get information, or find tools to help someone else. <https://www.thetrevorproject.org/>



SAMHSA's National Helpline - SAMHSA's National Helpline is a free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance use disorders. **1-800-662-HELP (4357)**



NAMI HelpLine - HelpLine volunteers are working to answer questions, offer support and provide practical next steps. The resources on this page provide information to address many needs and concerns.

