

**Formative Research to Develop HIV Social Marketing Campaigns for Healthcare
Providers**

**Attachment 4b: Exploratory Testing Guide
Patient Centered Care**

Public reporting burden of this collection of information is estimated to average 1 hour 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: PRA (0920-1182)

I. Welcome

Thank you for coming here today. Your participation is very important. I'm _____ and I'm from _____ (insert contractor name). The Centers for Disease Control and Prevention (CDC) is sponsoring this research. The purpose of this interview is to inform the development of messages and materials that will promote HIV testing, prevention, and care services for (insert population [e.g., transgender, substance using, etc.]) individuals. Therefore, we will be asking you questions about your experiences providing health care and HIV-related services to this population. Your insights today are crucial as they will aid in the development of HIV-related resources and materials for [insert population] patients and their providers. We really appreciate your time today.

[INTERVIEWER REVIEWS INFORMED CONSENT FORM]

- I know that you've had a chance to review the consent form and indicate your consent. Do you have any questions about the study or your participation before we begin? [Answer any questions.]

Before we begin, I want to review a few ground rules for our discussion.

- Your participation is voluntary, and you have the right to withdraw from the study at any time.
- We will be audio recording the interview [*If applicable*] and we have a live video stream. I want to give you my full attention and not have to take a lot of notes. After completing all of our interviews, we will be writing a report and will refer to the recording when writing the report.
- [*If in-person*] Behind me is a one-way mirror. Some of the people working on this project are observing this discussion so that they can hear your opinions directly from you and taking notes so that your opinions are accurately captured. [*If videoconference or telephone*] CDC staff members are observing via a live video stream/ listening via telephone.
- Your identity and anything personal you say here will remain private. Your name, address, and phone number will not be given to anyone and no one will contact you after this interview is over. The interview notes will be kept secure and separate from any identifiable information.
- The consent form that you just read has contact information for the project director, in case you have questions about the study, and contact information for RTI's Office of Human Subjects Projection in case you have questions about your rights as a participant.
- Most importantly, there are no right or wrong answers. We want to know your opinions and what you think about the materials we will be discussing. I do not work

for the people sponsoring this research and I did not develop any of these materials, so don't hold back on giving me your honest opinions.

- Please turn your cell phone to vibrate or silent mode. The interview will last no more than 1 hour.
- If you need to go to the restroom during the discussion, please let me know.
- Do you have any questions before we begin? [Answer any questions.]

II. Warm up

1. I would like to begin our discussion by asking you to introduce yourself and tell me:
 - your first name
 - number of years in practice
 - professional affiliations (HIV Medicine Association (HIVMA); American Academy of HIV Medicine (AAHIVM); American College of Physicians (ACP) American Academy of Family Physicians (AAFP); Society for General Internal Medicine (SGIM); National Medical Association (NMA); and National Hispanic Medical Association (NHMA); state and local organizations, Others?)
 - a description of your practice (size, number of patients with HIV seen per month)
 - your patients' insurance coverage (Medicare, Medicaid, HMO, private insurance, self-pay)
 - about the patients you see in your practice (men, women, transgender, diverse populations, age range)
2. Please tell me about some of the approaches your practice uses to create a [welcoming/holistic] environment for [insert population] patients.
 - Do clinic registration forms ask about [gender identity/substance use/etc.]?
 - **[If population is transgender]** Do staff ask patients how they would like to be addressed? Are patients allowed to use restrooms that match their gender identity? Does your practice have policies or procedures in place concerning gender identity and expression?
 - To what extent are physical and mental health services integrated within your setting?
 - How does your practice engage patients/families in their care? (E.g., patient and family advisory committees, patient representative on board of trustees, quality improvement committees, etc.)

III. Questions (Note that bulleted items are probes.)

Knowledge of Patient Experience

2. First, we'd like to learn about the types of [insert population] patients you treat. Please tell us a little about your [insert population] patients. (*Probe on each item below*)

- ***[If population is transgender]*** Self-identification (e.g., MTF/FTM/”gender queer”/other)
 - ***[If population is transgender]*** Stage of gender reassignment
 - Age group
 - Economic status
 - Housing status
 - Employment status
 - Sex work
 - Substance use history
 - Insurance status
 - Race/ethnicity
 - HIV status
3. ***[If population is transgender]*** As a care provider, how do you define a transgender person?
4. What kinds of services do you or other health professionals in your practice/facility provide to [insert population] patients? (*Probe on each item below*)
- ***[If population is transgender]*** Hormone therapy
 - ***[If population is transgender]*** Surgery
 - Mental health services
 - Substance abuse treatment services
 - Social support around [insert]
 - Psychiatric or psychological services
 - Gynecological
 - HIV-related services (e.g., testing, prevention, including pre-exposure prophylaxis, HIV treatment/ART) ***[Note: If participant mentions HIV services, mention that more specifics will be covered later in the interview.]***

Note: For question 5, do not repeat probes if participant addressed them previously (see question 2).

5. Would you describe your practice as [insert population]-friendly?
- If so, what specific steps did you take to make your practice [insert population]-friendly? (e.g., *as appropriate*, trans-friendly bathrooms, training for all staff, transgender staff, appropriate gender assignment on forms, harm-reduction approach to care, etc.)?
 - Do you actively seek [insert population] patients? If so, what approaches have you used? What approaches have proven effective?
 - If not, please describe any barriers you have faced or (potentially might face) to having a [insert population]-friendly environment.

HIV-Related Care

6. What kinds of HIV-related services and/or interventions do you or other health professionals in your practice provide to [insert population] patients? (*Probe on each item below*)
 - HIV testing (including HIV self-test)
 - Pre-/post-test counseling
 - HIV referrals/linkage to care
 - HIV medical care, such as prescribing ART or viral load, CD4 testing
 - Pre-exposure prophylaxis (PrEP)/post-exposure prophylaxis (PEP)
7. Can you tell me about how and when you might recommend HIV testing for one of your [insert population] patients?
8. Can you tell me about how and when you might recommend a HIV self-test for one of your [insert population] patients?
9. Can you tell me what you know about pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) as HIV prevention strategies for certain high-risk groups, including sexually active [insert population] patients and/or their partners?
10. Can you tell me what you know about prevention strategies for people with HIV, including Treatment as Prevention?
11. Can you tell me about when and how you discuss condom use as a HIV prevention strategy?
12. Based on what you know, would you consider PrEP to be an effective HIV prevention strategy for your patients?
 - What about PEP? Why or why not?
 - What about condoms? Why or why not?
 - What about Treatment as Prevention? Why or why not?
13. [***If population is substance users***] Thinking about your patients who are active substance users, how does substance use effect their ability to adhere to PrEP or ART? Among this patient group, what factors increase or decrease their risk of nonadherence? How have you addressed nonadherence among these patients in the past and to what extent do you think these approaches were effective?
14. [***If population is transgender***] Earlier you said you provide [*list services mentioned by the participant in Question 6 and hormone therapy (if applicable)*] to transgender patients. Would you be interested in offering [*hormone therapy and*] any of the following HIV-related services to transgender patients? [*list services NOT mentioned by the participant in Question 6*]? Which ones and why?
15. [*For services in Questions 6 and 12 that participant said “no” to*] What are some barriers to offering these services in your practice?
 - Is there any kind of information, resource, or tool that could be provided to you to make you more interested, comfortable, and willing to offer [service]? Please explain.

- [If yes] If you had access to this/these materials, would you be willing to provide [list services] to your transgender patients?
16. You said you'd be interested in providing [list services mentioned by the participant in Question 12] to [insert population] patients. How comfortable are you in offering [list each service mentioned by the participant individually from Question 12] to your [insert population] patients?
- [If participant expresses discomfort with any service] What kinds of resources or tools would help you feel more comfortable providing [list service]?

Patient-centered Care

17. Now we're going to switch gears a bit and talk about patient-centered care. First, I would like to know what patient-centered care means to you.
18. To what extent are patient-centered care approaches used in your practice? Are you comfortable with your practice's patient-centered care approaches? Why or why not?
19. How confident are you in your ability to provide patient-centered care? What would make you feel more confident in your ability to provide patient-centered care?
20. In your opinion, how is patient-centered care beneficial to patients? How do you think it effects overall service delivery?
21. What make it challenging to deliver patient-centered care? *[Probes, if needed: Time consuming, lack knowledge, lack of organizational support, etc.]*
22. How do you involve your patients in shared decision making about their care?
- How do you make sure your patient knows that a decision needs to be made?
 - How do you assess whether your patient wants to be involved in decision making?
 - How you explain treatment options to your patient, including the advantages and disadvantages of each?
 - How do you determine which option patients prefer?
23. What makes it challenging to involve your patients in decision making about their care? *[Probes, if needed: Time consuming, patients' health literacy, patients prefer that I tell them what to do, etc.]*

Psychosocial Issues

24. What are the top [number] barriers to accessing [HIV testing/HIV prevention/HIV care/health care] services by your [insert population] patients?
- Trauma/history of abuse
 - Homelessness/inadequate housing
 - Acceptance/rejection by family and friends
 - Substance abuse
 - Mental health/suicide risk

- Employment/sex work
- Gender identity
- Sexual identity
- Body image
- Surgeries/silicone
- Harassment
- Stigma
- Violence
- Discrimination
- Health insurance coverage
- Low income/financial barriers
- Other (specify)_____

25. Please consider the top 5 barriers you identified. How do you think each of these barriers could be addressed?

Provider Education

26. What kind of training have you received to enhance your skills/ capacity to work with [insert population] individuals?

- Was this sensitivity training or related to provision of their medical care?
- What topics were covered? Of these, which did you find most helpful?
- Who offered/sponsored this training? How did you access this training (e.g., online, in-person, CMEs, etc.)?
- Did others in your practice attend? Why or why not? What motivated you to attend this training? Why did you take part in this training?
- Have you ever received training related specifically to providing patient-centered care? If yes, what did the training entail? If not, would you be interested in learning more about this topic? Why or why not?

27. How often do you seek out new information about how to work with [insert population] patients? On what topics?

28. What websites do you use to learn more about treating [insert population] patients generally and on topics such as [insert topics here]?

29. Is there information or topics that you think would be helpful to you as a provider to [insert population] patients that you currently do not have access to? What topics?

30. What resources/materials/information would be helpful to help you address the HIV-related needs of your [insert population] patients? (E.g., HIV toolkit tailored to certain patient populations, website, CME course, a brochure, peer mentoring, list serve focusing on population-specific topics, etc.)

31. What kind of information on [topic such as adherence, risk reduction among HIV-positive patients or retention in care] would help you better serve your [insert population] patients?

- Probes: Specific tips for how to speak to your patients? Specific resources to refer to your patients? CDC publications on transgender health? Other tools?

Patient Education & Referrals

32. What printed materials do you have available for your [insert population] patients that address [insert topic here]?
- Where did these materials come from?
 - If none, why don't you have any materials available on this topic?
33. Do you provide [insert population] patients with [HIV/health] educational materials specifically designed for them? Why or why not?
- If so, what kinds of materials? Where did you get them?
 - If not, what stops you from providing your [insert population] patients with [HIV/health] educational materials specifically designed for them?
34. What, if any, HIV-related topics do your [insert population] patients ask you about?
- Which topics or questions do you wish you had more guidance and information to provide a better answer?
 - What about the format of the materials? Would you like any of the following?
 - Websites you could refer them to.
 - An online tool that you could use with them to understand risk.
 - A brochure you could hand to them.
 - Posters you could put in the waiting room.
 - Other?
35. What kinds of referrals for ancillary services [e.g., HIV, transgender, social, substance use or mental health treatment, etc.] are you able to make for your [insert population] patients? What other types of referrals/services would be helpful?
36. To the best of your knowledge, do your [insert population] patients have access to computers and the Internet?
- If yes...
 - Do you refer your [insert population] patients to any websites related to [insert topic here – HIV prevention, testing, care; hormones; PrEP/PEP, etc.]?
 - What are they?
 - If no...
 - Why might that be?
37. Do you ever refer your [insert population] patients to CDC's website for HIV information?
- If yes...
 - What do patients like about the website?
 - What do they dislike?
 - How can the website be improved?

38. In your opinion, what kinds of communication materials should CDC develop and/or adapt to encourage HIV prevention, testing, and treatment for [insert population]?
39. What websites do you use to learn more about [insert population] health topics?
- What do you like about these websites?
 - What do you dislike about these websites?
 - How can the websites be improved?
40. If CDC were to develop new materials for [insert population] on [topic such as adherence, risk reduction among HIV-positive patients or retention in care], how can we ensure that the imagery and content affirms gender identity and are culturally appropriate?
- How can we ensure that the imagery will resonate with [insert population]?
 - ***[If population is transgender]*** Using images of well-known or famous transgender individuals? Copy to describe that the people photographed are transgender?

IV. Closing

Okay, we are pretty much out of time.

41. Do you have any last thoughts?

[MODERATOR WILL CHECK WITH OBSERVERS FOR ADDITIONAL QUESTIONS OR COMMENTS.]

I would like to thank you for coming here today and working hard on this. This has been very useful in helping us to inform future HIV information, education, and communication efforts.