

## Instrument 7. Youth Focus Group

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### Pre-Focus Group Questionnaire

This questionnaire will need to be administered in the present of a case manager or support worker. Project team may help youth fill out the form if they have questions or issues with the text. Youth are allowed to decline to fill out the form.

Age	
Gender	
Sexual orientation	
Race/ethnicity	

How long have you been coming to this clinic?	
How long ago were you diagnosed with HIV?	

	<i>Don't know about this</i>	<i>Know a little bit this</i>	<i>Know about this</i>	<i>Know a lot about this</i>
<i>On a scale of 1-4, how would you rate your own knowledge of:</i>				
1. How to get and spread HIV	1	2	3	4
2. Different ways to prevent HIV (in addition to condoms)	1	2	3	4
3. What a viral load count is	1	2	3	4
4. What viral load suppression is	1	2	3	4
5. How adherence to anti-HIV medications can help suppress HIV	1	2	3	4
6. What PrEP and PEP are and how they are used	1	2	3	4

## **Name Tags**

Pass out name tags in advance of the focus group, and ask youth to put their preferred names or pseudonyms, and any other way they would like themselves identified.

## **Focus Group Guide**

### *Introduction*

Hi, I'm \_\_\_\_\_ and I work for [ORGANIZATION]. We are working on a project that looks at different treatment programs and clinics to see how we can make services better for youth living with HIV. We want to make sure that we include the thoughts and opinions of the people who have experience in this area, which is where you come in. Today we want to hear about your experience as a patient at [*provider organization*], and what keeps you coming here. We also want to hear about what you think could make it better. Your ideas and experiences are so important and we value everything you have to share.

### *Ground Rules*

We want you to do the talking. We would like everyone to participate and I may ask for your opinion if I haven't heard from you in a while. This is a safe space and a judgment free zone. As a group we want to be respectful and make sure that everyone's opinions are heard. There are no right or wrong answers. Please make sure your phones are turned off.

We'll have everyone introduce themselves (you can just use your first name if you like) and write the name you would like us to call you on the name tag. I want to let everyone know that you don't have to say anything you aren't comfortable with. You don't have to share personal information, and you can speak generally about what you have heard about peoples' experiences in this clinic.

I'd like to record our conversation today that that I can listen to it later when I write up notes. No one other than our project team will listen to the tape, and everything you say here is private – when we write our report, we will include a summary of peoples' opinions, but no one will be mentioned by name. If you want to say anything that you don't want taped, please let me know and I will be glad to pause the recorder. Does anyone have any objections to being part of the focus group or to my taping the discussion?

I am going to start recording.

I will be helping to guide the conversation and make sure everybody has the chance to speak. This is my colleague, \_\_\_\_\_. S/he will be taking notes during the conversation so that we do not forget any of the points discussed.

Are there any questions before we get started?

### *Overall Experience*

Great. We want to start by hearing about your overall experiences here.

- How long have you been a client here?
- What's it like being a client at this clinic?

- **Follow up:**
  - What makes it easy or difficult?
  - Do you feel heard?
  - What keeps you coming back here?
- When you have a problem, who do you turn to here at [ORGANIZATION]?
- How does this clinic fit in with everything else happening in your life?
  - **Follow up:**
    - Do you feel like it is important to come regularly? Why or why not?

*Systems and Infrastructure*

- What would you like to be different around here?
  - **Follow up:**
    - What would make you stop coming to this clinic?
- Do you think that teens here feel like the clinic is a safe space? If not, why?
  - **Follow up:** safety in waiting rooms, privacy/confidentiality
- Tell me about how appointments are scheduled for you?
  - **Follow up:**
    - What helps you keep appointments?
    - What does [organization] do to help you get and keep appointments with your doctor and other staff at this organization?

*Clinical Standards and Models of Care*

- What other kinds of health care or non-health care services are there for patients your age? Do you use them?
  - **Follow up:** mental health, adherence counseling, labs, dental, counselors, substance abuse, support groups, housing support, lawyers

Now let's switch topics a little bit. We want to hear about your thoughts on your treatment.

- What does viral suppression mean to you? Viral suppression is the aim of HIV care, which means that you have been undetectable for quite some time.
  - **Follow up:**
    - What do you think of when doctors talk to you about viral load?
    - How do you think viral load is important?
    - Do other clinic staff talk to you about viral load? Who?
- What do you think are the 2-4 most important things your care team does to help you manage your HIV?

- What supports medication adherence for you?
  - **Follow up:**
    - Does anyone check in with you to make sure you're taking your medicine?
    - Do you get support from family and friends to help you remember to take your medicine?
- How does the clinic work with you on how you are going to manage your HIV long-term? Do you agree with this plan?
- Does the clinic communicate with you in any way using technology (like Facebook or texts)? If yes, do you like this? If not, would you be interested in this?
- **For those who are older**, has anyone talked to you about the transition to adult clinics? Do you feel prepared?

*Provider and Care Team Knowledge, Skills and Attitudes*

- Do you feel like your health care provider and team takes time to get to know you and fully understand your specific situation? If so, how do they do that?
  - **Follow-up:** Can you give some specific examples of when you feel like your provider met you where you were with your HIV care, and addressed your specific life, problems, preferences family issues, etc.
- Do you feel respected as a teen? How does the clinic staff make you feel regarding your HIV, and the decisions you make about your care?
- How do providers talk to you about sex?

*Collaboration with Youth and Families*

- Outside of this clinic, who is most important in helping with your HIV care and treatment?
  - **Follow up:** Does the clinic work with your families, partners, and friends to help with your care and treatment?
- Does the clinic have any special group programs for teens (e.g. job skills training, social events)? Do you participate in them?
- Do you have a way to give feedback to the clinic on your care, services here, and/or to ask for different services?

*Community Presence and Linkages*

- How does the clinic link you with other services you might need that they don't have?
- Is the clinic known in the community? If so, what do people think of it?

*Wrap-Up*

- How does this clinic help you feel good about yourselves and your care?

Thank you so much for speaking with us. What you have to say is really important, and we will use it to try to make services better for all youth with HIV.

Is there anything else you would like to share that you did not get to say earlier?