Instrument 8. Youth Interview

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Thank you very much for agreeing to speak with me. I'm [NAME] and I work for [ORGANIZATION]. We are working on a project that looks at different treatment programs and clinics to see how we can improve services to 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.

I want you to know that this is a safe space and a judgment free zone, and there are no right or wrong answers. Everything that you tell me will be private. When we write our report, we won't mention anyone by name.

I'd like to record our conversation today so 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. Do you have any questions for me before we get started?

To start, I would like to learn a little more about you.

- How long have you been coming to this clinic?
- How did you first hear about [organization]?
- How do you like this clinic compared with any other places you might have gone for HIV services?

Overall experience

Now, we would like to hear a bit more about your overall experiences here.

- 1. What's it like being a patient at this clinic?
 - Follow up:
 - What makes it easy or difficult?
 - Do you feel heard overall?
- 2. What keeps you coming back here?
- 3. When you have a problem, who do you turn to here?
- 4. 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

- 5. What would you like to be different around here?
 - Follow up:
 - What would make you stop coming to this clinic?
 - Has anyone you know stopped coming, and why?
- 6. 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
- 7. 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?
- 8. How are your interactions with staff that greet you?
- 9. How do you feel about the way your information is handled? Do you feel that it is secure?

Clinical standards and models of care

- 10. 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
- 11. 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?
 - Why do you think viral load is important?
 - Do other clinic staff talk to you about viral load? Who?

- 12. What do you think are the 2-4 most important things your care team does to help you manage your HIV?
- 13. 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?
- 14. How does the clinic work with you on how you are going to manage your HIV long-term? Do you agree with this plan?
- 15. 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?
- 16. Has anyone talked to you about the transition to adult clinics? Do you feel prepared?

Provider and care team knowledge, skills and attitudes

- 17. Do you feel like your doctor and others here take the 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.
- 18. 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?
- 19. How do providers talk to you about sex?
 - **Follow up:** Do they talk about how to keep partners safe?

Collaboration with youth and families

- 20. 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?
- 21. Does the clinic have any special group programs for teens (e.g. job skills training, social events)? Do you participate in them?
- 22. Do you have a way to give feedback to the clinic on your care, services here, and/or to ask for different services?
 - If yes, please tell me more about the ways you can do this
 - If no, please tell me about what you think they could do to make sure your feedback was heard

Community Presence and Linkages

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