

Attachment B: Ryan White HIV/AIDS Program Viral Suppression Client Survey Guide

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INTRODUCTION

Good Morning/Afternoon. Thank you for agreeing to participate in this Ryan White HIV/AIDS Program or “Ryan White Program” client interview. My name is [NAME]; I work at Abt Associates, a research and consulting firm based in Cambridge, Massachusetts. Abt has been contracted by HRSA/HAB to conduct a project to learn about client’s experiences and opinions about their HIV services. We are part of a team of interviewers who are meeting with clients and staff in 25 sites like this one around the country.

We are interested in learning about effective programs and what programs and health care providers can do to assist clients in staying healthy. In addition, we are interested in particular things like stressful life events and how they may affect you and your ability to use health services and stay healthy. We are particularly interested in your experience with achieving and maintaining viral suppression.

You were chosen for this project because you received, or have received, Ryan White HIV/AIDS Program-funded services at [SITE NAME]. The information you provide will be very valuable in helping HAB determine the future direction of services provided under the Ryan White HIV/AIDS Program.

This survey will take approximately 30 minutes to complete. I will ask you questions about your background, experiences accessing healthcare, experiences receiving healthcare and support services, experiences with others in your family or community, and questions about taking care of yourself. As a reminder, I will be asking some questions on sensitive topics that could be upsetting for you. You do not have to answer any questions that make you feel uncomfortable and you can stop at any time or let me know if you need to take a break. Do you have any questions for me before we begin?

I want to start with asking you some general questions about your background.

A. Demographics

1. What is your age in years?

2. What was your sex at birth? (Select one)

- Male
- Female
- Intersex/ambiguous
- Refused to Answer

3. Do you consider yourself to be male, female, or transgender?

- Male
- Female

- Transgender
- Refused to Answer

4. Do you think of yourself as: (Select one)

- Lesbian or gay
- Bisexual
- Straight, that is, not gay
- Something else

Please specify: _____

- Refused to answer
- Don't know

5. The next question is about your current legal marriage status. Are you currently: (Select one)

- Married
- In a civil union or domestic partnership
- Divorced
- Widowed
- Separated
- Never married
- Refused to answer

6. Are you currently living with your husband, wife, boyfriend, girlfriend, or partner? (Select one)

- No
- Yes
- Refused to answer

7. Do you consider yourself to be Hispanic or Latina? (Select one)

- No, not Hispanic, Latina
- Yes, Mexican, Mexican American Chicana
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latina
- Refused to answer
- Don't know

8. What is your race? You may choose more than one option category? (Select all that apply)

- American Indian or Alaska Native
- Asian
- Black or African-American
- Native Hawaiian or other Pacific Islander
- White
- Refused to answer
- Don't know

9. What is the highest level of education you have completed? (Select one)

- Never attended school
- Grades 1 through 8
- Grades 9 through 11
- Grades 12 or GED
- Some college, Associates Degree, or Technical Degree
- Bachelor's Degree or greater
- Refused to answer
- Don't know

10. In the last year, what was your combined yearly household income from all sources before taxes?

When I say “combined household income”, I mean the total amount of money from all people living in the household.

- 0 to \$4,999 per year
- \$5,000 – \$9,999 per year
- \$10,000 - \$12,499 per year
- \$12,500 - \$14,999 per year
- \$15,000 - \$19,999 per year
- \$20,000 - \$24,999 per year
- \$25,000 - \$29,999 per year
- \$30,000 - \$34,999 per year
- \$35,000 - \$39,999 per year
- \$40,000 - \$49,999 per year
- \$50,000 - \$59,999 per year
- \$60,000 - \$74,999 per year
- \$75,000 or more per year
- Refused to answer
- Don't know

11. Including you, how many people depend on this income in the past year?

____ [NUMBER]
 Refused to answer

12. Are you currently: (select one)

- Employed for wages
- Self-employed
- Out of work for more than 1 year
- Out of work for less than 1 year
- A homemaker
- A student
- Retired
- Unable to work
- Refused to answer

13. During the past 12 months, have you done any of the following (select all that apply):

- Lived on the street
- Lived in a shelter
- Lived in a Single Room Occupancy (SRO) hotel
- Lived in a car
- Refused to answer

14. How long have you been living at your current address?

Years _____

Months _____

- Refused to answer
- Don't know

B. Access to Care and Health Care Coverage

The next set of questions I will ask are about health care coverage.

1. When were you first diagnosed with HIV?

[YEAR]

This information will be flagged for future questions to provide timeframe of question/response.

2. Do you currently have health care coverage?

a. If yes, what type of coverage is it?

b. How long have you had this health care?

3. If yes, has this health care coverage helped you access HIV care and medication? If so, how?

4. If yes, has this health care coverage caused any problems for you in getting HIV care and medication? If so, how?

5. If yes, have you had any interruptions in your health coverage in the past year? If yes, please describe the situation or circumstances leading to your interruption.

C. Stigma

Now I am going to ask you some questions about how you may have felt or worried about things like disapproval or judgement from others related to your HIV status. Please answer each one of these questions by selecting the number of the answer that most closely reflects your experience:

Interviewer note: Please use response card C to answer the following questions.

1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

1. In the past year have you ever:

- a. Felt having HIV was a punishment for things you had done in the past
- b. Felt that people were avoiding you because of your HIV status
- c. Feared that you would lose your friends if they learned about your HIV status
- d. Felt like people that you know were treating you differently because of your HIV status
- e. Felt like people looked down on you because you have HIV
- f. Avoided dating because you believed most people do not want a relationship with someone with HIV
- g. Avoided a situation because you were worried about people knowing you have HIV
- h. Been embarrassed about having HIV
- i. Felt that keeping your HIV status secret was important

Interviewer note: The following questions are Yes or No answers.

2. Since you were diagnosed with HIV has any health care provider (doctors, nurses, clinic staff, etc.):

- a. Acted uncomfortable with you?
- b. Treated you as an inferior?
- c. Preferred to avoid you?
- d. Refused your service?

3. If yes to A, B, C, or D, has this caused you to avoid HIV care as a result?

D. Medical Mistrust

Now I am going to make some statements related to the trustworthiness of health care organizations. This could include any place you have received health care services. Please rate your level of agreement with these statements using this agreement scale:

Interviewer note: Please use response card D to answer the following questions.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

- a. You should be cautious when dealing with health care organizations.
- b. Clients have sometimes been deceived or misled by health care organizations.
- c. When health care organizations make mistakes they usually cover it up.
- d. Health care organizations have sometimes done harmful experiments on clients without their knowledge.
- e. Health care organizations do not always keep your information totally private.
- f. Sometimes I wonder if health care organizations really know what they are doing.
- g. Mistakes are common in health care organizations.

E. Trauma History and Current Exposure

In the next section of the interview, I will ask questions about events that sometimes change people's lives, like the death of a friend or family member, illness or injuries, and employment or relationship issues, as well as other events. Some of the questions are very personal and ask about sensitive topics that could be upsetting to you. Please take as much time as you need to answer each question. Also, please remember that everything you tell me is confidential and you do not have to answer any questions you are not comfortable answering. You can stop at any time.

Interviewer note: Please use response card E to answer the following questions.

1	2	3	4	5	7	8
Extremely stressful	Very stressful	Moderately stressful	A little stressful	Not stressful	RF	DK

1	2	7	8
Yes	No	RF	DK

1. First I am going to ask you about events in your relationships. Since (12-MO/DATE), have you
 - a. gotten married, engaged or made a formal commitment to a partner, including a ceremony
 - i. If yes, when it occurred, how would you rate your stress using the scale?
 - b. gotten divorced, separated or had a break-up with a partner (mate/girlfriend/boyfriend) (must have been in the committed relationship at least 6 months)
 - i. If yes, when it occurred, how would you rate your stress using the scale?
2. Now, I am going to ask you about any experiences with death of people who are very close to you. Since (DATE), have you experienced the death of a close family member or very close friend?
 - i. If yes, when it occurred, how would you rate your stress using the scale?
4. Since (12-MO DATE), have any close family members or very close friends experienced a serious illness or injury (READ CATEGORIES)? (Please do not include those whom you have mentioned that died.)
 - i. If yes, when it occurred, how would you rate your stress using the scale?

Now, I am going to ask you about problems with work and finances

6. Since (12-MO DATE), have you been employed at any time?

a. (If yes). Since (DATE) , have you had trouble with your employer such as being in danger of losing your job, being suspended or demoted, experiencing discrimination, or any other major problems with your job?

b. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

7. Since (12-MO DATE), have you lost your job, that is: you were you fired, laid off, quit, or retired?

a. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

8. Since (12-MO DATE), have you been out of work for at least 2 months?

a. (If yes) During that time while you were out of a job, were you seriously looking for a job?
b. (If yes) How stressful or difficult was this? Would you say it was (READ OPTIONS)?

9. Since (12-MO DATE), did you experience any financial problems?

i. If yes, when it occurred, how would you rate your stress using the scale?

10. Since (12-MO DATE), have you or a partner become pregnant, had a baby or adopted a baby?

a. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

Now, I am going to ask you about illness, accidents, and injuries. As a reminder, all your answers will be kept confidential and you may skip any question you do not wish to answer. You may also end the interview at any point.

15. Since (12-MO DATE), besides illness related to HIV infection, have you had a major illness, chronic health problem or injury?

a. Were you hospitalized?
b. When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

11. Since (12-MO DATE), were you physically attacked or assaulted or had your life threatened?

a. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

12. Since (12-MO DATE), were you sexually abused or assaulted? That is, did anyone touch your sexual organs (breasts, penis, vagina, anus, etc.) or make you touch their sexual organs by using force or threatening to harm you?

a. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

13. Since (12-MO DATE), have you felt unsafe in your neighborhood?

a. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

Now I will be asking you about any history of interactions with law enforcement/police.

14. Since (12-MO DATE), have you been arrested for a serious crime such as, driving under the influence of alcohol or drugs, robbery, drugs, or a crime involving more than just a fine?

a. When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

15. Since (12-MO DATE), were you convicted of a crime and sent to jail or prison?

a. (If yes) How many days were you in jail or prison? (RANGE 001-270# OF DAYS)
b. When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

16. Since (12-MO DATE), was a friend or close relative arrested for a serious crime, with likely jail or prison sentence, or sent to jail or prison for at least one month?

a. When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

17. Since (12-MO DATE), were you robbed or was your home burglarized?

a. When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

18. Since (12-MO DATE), did you move your residence more than once?

a. (If yes) When it occurred, how stressful or difficult was this? Would you say it was (READ OPTIONS)?

F. Coping Self-Efficacy

For the last set of questions, I am going to ask you some questions about your confidence in your coping skills.

Since (12-MO DATE):

	Not at all	Used some what	Used quite a bit	Used a great deal	REF	DK
1a. I knew what had to be done, so I doubled my efforts to make things work.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1b. I made a plan of action and followed it.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1c. Just concentrated on what I had to do next – the next step.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1d. Changed something so things would turn out all right.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1e. Drew on my past experiences; I was in a similar position before.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1f. Came up with a couple of different solutions to the problem.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1g. Changed or grew as a person in a good way.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1h. I came out of the experience better than when I went in.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1i. Found new faith.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1j. Rediscovered what is important in life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1k. I prayed.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1l. I changed something about myself.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98
1m. I was inspired to do something creative.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 97	<input type="checkbox"/> 98

G. Case Adherence Scale

The next few questions I will ask are about taking your HIV medications. I will give you several answer choices for each question. Please select the answer that most accurately represents your experience.

(Directions from tool: Please ask each question and circle the corresponding number next to the answer, then add up the numbers circled to calculate Index score.)

Interviewer note: Please use response card G to answer the below questions.

1. How often do you feel that you have difficulty taking your HIV medications on time? By “on time” I mean no more than two hours before or two hours after the time your doctor told you to take it.

1	2	3	4
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All the time	Most of the time	Rarely	Never

2. Thinking of the last 3 months, how often would you say that you missed at least one dose of your HIV medications?

1	2	3	4	5	6
Everyday	4-6 days/week	2-3 days/week	Once a week	Less than once a week	Never

3. When was the last time you missed at least one dose of your HIV medications?

1	2	3	4	5	6
Within the past week	1-2 weeks ago	3-4 weeks ago	Between 1 and 3 months ago	More than 3 months ago	Never

H. Substance Use

Now I would like to ask you about experiences related to alcohol or drug use (DEFINE) that you have had in the past 12 months.

1. Since (12-MO DATE),, have you drunk an alcoholic beverage (wine, beer, malt beverage, liquor) and/or used drugs (including non-medical use of prescription drugs)?

[If NO to Q1, SKIP to SECTION I]

	Yes	No	Don't Know	Refused to Answer
2a. Have you spent more time drinking or using drugs than you intended?				
2b. Have you neglected some of your usual responsibilities because of alcohol or drug use?				
2c. Have you wanted to cut down on your drinking or drug use?				
2d. Has anyone objected to your use of alcohol or drug use?				
2e. Have you frequently found yourself thinking about drinking or drug use?				
2f. Have you used alcohol or drugs to relieve feelings such as sadness, anger, or boredom?				

I. Closing

1. Now, thinking about all the things we discussed here, can you tell me what two things you believe are most important for you in managing your HIV.

Probe: explain how these are important to managing your HIV... or give an example of a time when a service helped you better manage your HIV (e.g., through accessing HIV care, treatment adherence, etc.)?

2. Are there any important points that you want to be sure we are aware of, that we did not talk about already?

Thank you for your participation, this information will be very helpful to HRSA.

We have finished our interview. On behalf of our project team, thank you very much for your participation today. We appreciate your feedback and that you were willing to share your experience with us. Sometimes questions like these can trigger memories or raise questions about your health. If any of the things we discussed today raised concerns for you about your health, please discuss them with your physician.

Thank you again. The information you provided will help HRSA design and fund services to help people with HIV.