

Attachment X: Ryan White HIV/AIDS Program Outcomes and Expanded Insurance Coverage– Focus Group Guide

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VERBAL CONSENT CONFIRMATION

[Facilitator Note: read the consent language below]

Abt Associates invites you to participate in a research study about how the changing healthcare landscape is affecting individuals who have traditionally received services through the Ryan White HIV/AIDS Program. We know that some people have gotten new forms of healthcare coverage and that getting that coverage might have changed how they get care. We also want to understand how Ryan White HIV/AIDS Program sites like this one are meeting the needs of clients since receiving healthcare coverage.

This study is funded and overseen by the Health Resources and Services Administration, HIV/AIDS Bureau, or HAB. HAB is the government entity that funds and directs the national Ryan White HIV/AIDS Program. The Ryan White HIV/AIDS Program funds nearly 2,000 HIV service providers like [SITE NAME]. HAB has engaged Abt Associates to conduct this study.

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

What will my participation involve?

If you decide to participate in the study, you will participate in a one and a half hour focus group with 7 to 9 other people who also receive services from [Site Name], a discussion leader, and a note-taker. The discussion leader will ask you about your experiences receiving care and with different types of healthcare coverage. During the discussion, you will provide only your first name. You can choose not to answer any of the questions. You may leave the focus group at any time.

We will take notes of this discussion. Only members of the research team will have access to those notes. Your name will not appear in any of the reports or papers resulting from this study. We will store all the electronic notes on a secure server.

Are there any risks?

Your participation is voluntary and involves no significant risks to you. Whether or not you participate, it will have no effect on your relationship with [SITE], any other organizations, or the Ryan White HIV/AIDS Program. We will not share any information about you with anyone outside the research team. With any study, there is always a risk of a breach of confidentiality, meaning that other participants in the group may reveal what was discussed in the focus group, or people outside the research team will see the information you provide. However, the study has procedures to protect your confidentiality discussed below.

How will you protect my information?

The information you provide in the interview will be kept confidential. Your name will not appear in any internal or published reports from the study.

Are there any benefits?

There are no immediate benefits to you. However, we expect that the results will help HAB determine the future directions of the Ryan White HIV/AIDS Program and the services it provides.

Will I be paid for participating?

We will provide a \$20 gift card to [STORE NAME] to compensate you for your time.

Who should I contact if I have questions?

If you have questions about the study or your rights as a research participant, please feel free to contact the study director, Michael Costa, MPH of Abt Associates Inc. at 617-349-2873 or by email at Michael_Costa@abtassoc.com. If you have questions about your rights as a research participant, you may contact Katie Speanburg, the Abt Institutional Review Board Chairperson at (877) 520-6835.

Consent to participate in this study

When asked by the facilitator, please provide a verbal “yes” to indicate that you have read the information in this consent form, and voluntarily agree to participate in this study.

Thank you all for agreeing to participate. My name is [NAME] and I work for Abt Associates, I'll be leading today's group. [NAME] is also with Abt Associates and will be taking notes during today's group.

Let's get started by going over some focus group ground rules.

- We ask that, to the extent possible, everyone speak one at a time so that we do not miss any information.
- Please be respectful of the opinions of others.
- We are not seeking agreement on anything in today's group.
- Please respect one another's privacy and do not share anything you hear in today's focus group with anyone outside of the focus group.
- Feel free to ask me questions at any time.

In today's session, I'll begin by describing some of changes in the healthcare landscape. You may already be familiar with them, but I just want to be sure we are all talking about the same things.

When we talk about **Medicaid** today, we are primarily talking about Medicaid Expansion/Newly Eligible Medicaid - Expanded Medicaid eligibility to include persons with income levels at or below 138 percent of the FPL, without a disability determination from the Social Security Administration.

Marketplace Insurance/Qualified Health Plan (QHP) refers to a health insurance plan that is approved by a Federal or State-run Marketplace.

When we refer to having **no healthcare coverage** we mean that you do not have those or any job-based insurance, Medicare, VA, etc.

In this first section, I'd like to start by finding out the different of types of healthcare coverage that everyone in today's group has or has had since January 2014.

A. Focus Group Participant Coverage (10 min)

1. Let's go around the room and do introductions. Please tell us:
 - Your first name.
 - How long you have been coming to this clinic.
 - Whether you have any type of healthcare coverage and what kind, for example, private insurance, Medicaid, VA or Medicare?

PROBES

- *If Medicaid, did you become eligible for because of the changing healthcare landscape, or did you have Medicaid before that?*
- *If private insurance, did you obtain that through as a result the changing healthcare landscape?*
- *If uninsured, have healthcare coverage of any kind since January 2014*

B. Core HIV Medical Services (20 min)

These next questions will focus on changes in the kinds of HIV medical services available to you through healthcare coverage because of the changing healthcare landscape. HIV medical services might include office visits for check-ups with your doctor, or lab tests like viral loads and CD4 tests.

We also want to learn about any changes to the kinds of HIV medical services you get now compared to those you got through this site's Ryan White HIV/AIDS Program before January 2014.

[Facilitator Note: track the types of coverage for each respondent]

1. Can everyone tell me which HIV medical services you feel are most important in helping you manage your HIV?
2. For those of you who got some type of new healthcare coverage, did getting that coverage result in any changes in the types of medical HIV services you get or where to go to get them? If yes, please describe.
 - 2.1. When you got your new coverage, were there any HIV medical services you could not get anymore?
 - 2.2. Have the number of HIV medical service visits available to you changed in anyway because of having new coverage?
 - 2.3. Did you see new or different HIV medical service providers because you got new coverage?
 - 2.4. Did you go to new or multiple locations for HIV medical services because you got new coverage?
3. Has there been any change in your wait time to get an appointment for HIV services with new coverage?

PROBES

- *Longer or shorter wait times?*
 - *No noticeable change?*
4. For those of you without healthcare coverage, have there been any changes in the types of HIV medical services you get or where you go to get them since January 2014? If yes, please describe.

C. Non-HIV Medical and Primary Care services (15 min)

Next, we are going to discuss medical and other primary care services not necessarily directly related to HIV care, this could include things like hypertension, diabetes, hepatitis or any other physical issues.

[Facilitator Note: track the types of coverage for each respondent]

1. For those of you who got new healthcare, did this new coverage help you get any non-HIV medical services? If yes, please describe.

- 1.1. Did you see new or different medical service providers to get those services?
- 1.2. Did you go to new or multiple locations to get those services?

2. For those of you without healthcare coverage, where do you go if you have health needs that are not related to HIV
 - 2.1. How do you get those services?
 - 2.2. Did you see new or different medical service providers to get those services?
 - 2.3. Did you go to new or multiple locations to get those services?

D. Pharmaceutical Services (15 min)

Now we are going to discuss access to HIV and other prescription medications

[Facilitator Note: track the types of coverage for each respondent]

1. For those of you who got new healthcare, did your new coverage result in any changes in your HIV medications? If yes, please describe.

PROBES

- *Did you have to change medications?*
- *Do you go to a different pharmacy to get your HIV medication?*
- *Is getting your HIV medication any easier or harder?*
- *Does it cost you any more to get your medications?*

2. For those of you without healthcare coverage, who pays for your HIV Medications?

PROBES

- *ADAP?*
- *Other?*
- *Has it changed since January 2014?*

3. Has anyone who got new healthcare coverage changed lost or dropped their coverage for HIV medications?

- 3.1. Can you tell us why?
- 3.2. Please describe what happened.
- 3.3. Has it happened more than once?

PROBES

- *Did you have any gaps in your medications because of not having coverage?*
- *How long were these gaps?*

E. Support Services (15 min)

Now, let's talk about any of the services you receive that are not strictly medical services. This includes everything from case management and housing assistance to transportation and food. I'll refer to these services as "support services."

[Facilitator Note: track the types of coverage for each respondent]

1. What support services are you currently receiving?
2. Can everyone tell me which support services you feel are most important in helping you, personally, to manage your HIV?

PROBES

- *Why do you feel these services are most important?*

For this next set of questions I'd like you to think about how things were before any changes in the healthcare landscape, compared to how things are now.

3. For those of you who got new healthcare coverage, did getting coverage result in any changes in the types of support services you get or where you go to get them? If yes, please describe.
 - 3.1. Did you lose access to any support services you were used to getting because of having coverage?
 - 3.2. Have the number of support service visits available to you changed in anyway because of having coverage?
 - 3.3. For people who had to go elsewhere for primary care due to their new coverage, did you continue to get support services at their usual RWHAP provider? Why/not?
 - 3.4. Were any new support services available to you because of having coverage?
4. For those of you without healthcare coverage, have there been any changes in the types of support services you get or where you go to get them since January 2014? If yes, please describe.
 - Are there any support services you used to get that are not available anymore?
 - Have the number of support service visits available to you changed in anyway?

F. Coverage Cost-Sharing (10 min)

Before we go through the next set of questions I'd like to review a few definitions:

- **Health Insurance Premium** - The amount you pay for a health insurance plan. A premium may be paid every month, every three months, or every year. Part or all of your premium may be paid by your employer, ADAP, or someone else.
- **People with health insurance may have to pay for part of their healthcare services. This is also referred to as cost sharing. You must pay for healthcare costs that aren't paid by the insurance plan "out of your own pocket."** Out-of-pocket costs include:

- o Deductibles
- o Coinsurance
- o Co-payments for covered services
- o All other costs for any services your insurance plan doesn't cover

[Facilitator Note: track the types of coverage for each respondent]

1. For those who have or had coverage since January 2014, did you, or do you get any assistance paying for the insurance plan "the premium?"

1.1. If yes, how much assistance? Who provides the assistance?

PROBES

- *Do you pay any of the insurance premium cost yourself?*
- *How much of the insurance premium cost do you have to pay out of pocket?*

3. Does anyone in the group have to pay any money when you go to get services or medications; things like deductibles, co-insurance or co-pays? These are sometimes called out-of-pocket costs.

3.1. If yes, please describe.

1.2. Do you get any assistance paying these costs? Who provides the assistance?

4. Do these out of pocket costs that you have to pay directly ever prevent you from getting care, or cause to you go to the doctor less often? If so, please describe those situations.

5. Do you ever find it difficult to get the medications you need because of these costs? If so, what difficulties have you had? Have you ever had to skip medications because of costs?

G. Closing (5 min)

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