

## Client Interview Guide

The following guide addresses issues raised during the September 2003 SPNS Outreach Initiative Interviewer Training Workshop and subsequent conference calls. In the interest of ensuring uniformity of data collection, CORE provides the following written guidelines regarding the explanation of questions, interpretation of responses, and coding of responses.

### **General information**

#### **Be sure to go through the entire survey with the client.**

Sometimes when you ask a person one question (e.g., if they ever saw a health care provider for HIV medical care) you get a story that includes answers to subsequent questions. You cannot skip the subsequent questions, because they might be asked slightly differently or have different response options. But at the same time, you may want to acknowledge that the person has already told you the answer so that they know you are listening to them. One suggestion is to preface the question(s) with a statement such as, “I know you already told me the answer to this question/some of these questions, but I need to ask them again for the study to be sure I have it exactly right.”

**Do not change client responses after the fact.** For example, a person may say at intake that they never used any drugs. Then during the follow up survey, they may say they did use a drug in the past. Do not go back and change the intake data.

**Skip patterns:** There are several places in the survey with instructions to skip the next several questions based on a client’s response to a previous question. If there is an instruction to skip, be sure to code “N/A” or 888 for the skipped question(s). Do not code with any other values. For example, if a client responds “yes” to “Are you currently taking medication for HIV?”(HIVRX), All reasons why not taking medication variables should be coded “N/A” or 888.

#### **“Don’t Know” values and implementation of skip patterns**

For most of the questions, try to obtain “yes”/ “no” responses. If client continues to respond, “I don’t know”, you do not have to follow the skip pattern. Simply continue to ask the next question in the survey.

**Refuse to answer should be coded as missing.** People may refuse to answer some questions, and some grantees want to track this. You can do that for your local evaluation, but for the multi-site evaluation code it as missing. We are not including a response option in Phase 2 for “Refused” for the multi-site evaluation. It was included in Phase 1 and was rarely used.

**Coding N/A:** The use of the code “N/A” should be used according to the instructions given in the survey and primarily when you are skipping questions. For example, If a client answers “no” to questions 21a, the instructions are to code “N/A for questions 21b to 34 and then proceed with question 35.

However for questions like “What are the reasons you do not take “HIV medications?” The responses here should be either “yes” or “no” to each item. N/A should only be used if you are skipping question 36. N/A is not a substitute for the response option “no”.

**If you are asking a question then try to get a concrete response (i.e., yes/no or another response option.) Avoid checking off “don’t know, N/A, or missing.**

### **Follow-up Interviews (6-,12-18,24 months)**

As you conduct your follow-up interviews several of the questions begin asking a 6 month time frame. For example: “In the last 6 months, how many times did you see your health care provider...” Some participants may be returning for follow-up interviews either earlier or later than 6 months, not exactly at 6 months. (Recall that follow-up interviews should be conducted within a 30 day window period). In addition, some participants may have difficulty with comprehending time frames and what they did 6 months ago, and providing a reference date or month can help ensure accurate answers. In order to facilitate responses and ensure we are capturing all the data possible in previous 6 month time frame, you may use the following probes with participants:

“Since your last interview with us in \_\_\_\_ (give date), how many times did you see a provider?”

If participants don’t clearly remember, try to use discrete events in time that may help them. For example if there was a holiday or special program gathering ie. Some event that may help them with recalling their activities in the previous 6 months.

### **Information for Specific Questions on the Intake Questionnaire**

#### **I. Demographics Section**

For Q. 2 If the individual answers transgender or transsexual in response to this question, there is no need to ask the question again in Q3; simply code Yes and skip to Q4.

For Q.5 What is your race/ethnicity? Comment: this question just asks about race, not ethnicity, so it is confusing people. Hispanic or Latino individuals will answer Hispanic or Latino, not one of the other categories.

Q: What do we do about this?

A: It is confusing, but this is the new way HRSA is collecting data and this is how they want us to do it too. So, if a person answers Hispanic or Latino, ask them if they consider themselves to be White Hispanic/Latino or Black Hispanic/Latino and code their response. If they still say, I’m Hispanic or Latino, enter “Other” and the response they give you. Then code yes to Q6 and skip to Q7. If they say white or Black Hispanic/Latino, code the race in Q5 and the code for Hispanic/Latino in Q6.

For Q. 15. What is your current relationship status? The first option is “legally married.” Actually, we don’t care if the marriage is legal or not nor do we wish to engage in debate about marriages sanctioned in Canada or Vermont but not elsewhere. If the person considers himself or herself to be married, whether legal or not, code 1 “legally married.”

For Q. 16. What was the highest grade in school you completed? If the person attended 6-8 months of vocational training after high school, code 13. We will end up making categories for the answers to this question – knowing if the person finished high school is important, but the difference between 13 and 15 years is not likely to matter very much for the analysis.

For Q. 17 Health Insurance, response b. “Medicaid.” Medicaid is called different things in different states. In California it is Medi-CAL, in Massachusetts it is MassHealth, and in Oregon, the Oregon Health Plan. It is fine to substitute the state-specific name of the program for Medicaid if this makes it easier for people to answer the question. If the person does not know what kind of insurance they have, or seems confused, ask if you can look at their insurance card.

For Q. 18. asks for household income. If the individual lives in a congregate setting such as a residential treatment program, use the individual income. However, for people who live with other individuals, either family or non-family, but who share expenses, we want to know household income. If the client does not know or cannot estimate the income of other members of the household who share expenses, code “Don’t know.”

## **II. Health Care for HIV Section**

For Q. 21.a. The intent of this question is to find out if the individual ever saw a health care provider for HIV primary care (rather than emergency care). Where it asks “at his/her office,” if the person received care in prison, or at a shelter or some alternative location other than an emergency room or inpatient hospital, that counts as a “yes.” You may omit the words “at his/her office” if you think this will confuse people.

For example, you may use the words “did you ever see a health care provider either at an office, clinic, anyplace except an emergency room or in hospital admission.” We realize that people may see a doctor at their place of residence maybe a mobile unit, etc. We want to include those visits but not any times they went to an emergency room.

If a client answers “no”, probe further to ensure that they have never seen a health care provider at an office, clinic, or anyplace else except an emergency room or hospital admission. For example, “Just so I understand: “Have you EVER seen a health care provider at an office, clinic or anyplace not including an emergency room or in-hospital admission.”

Q: If a person answers that they have never seen a health care provider for their HIV, why do we skip to Q. 35, which asks if they are currently taking medications for HIV? We know the answer is no.

A: We ask this question for two reasons. First, we want a full count of people who are taking medications and people who are not taking medications. We do not want this question coded as N/A because it is part of a skip pattern. Second, if they answer no, the next question asks about the reasons. People who have never seen a health care provider for HIV may have important reasons for not taking medications that we want to capture.

For Q21b: After you first tested positive, how long was it before you saw a health care provider for your HIV?

For this question, if a person received their test results and also received some form of treatment from a health care provider (for example, a prescription for PCP prophylaxis, ordered blood tests, etc) on the same day, then write in the response “ less than one week.” Don’t worry about the units of measurement, and if the response is weeks, months or years. Record the exact length of time as described by the client. Data entry personnel will re-code to the appropriate time measure into weeks.

For Q 23: What is the longest time you went without seeing a health care provider?

The answer to this response should be equal to or greater than the client response in 21b. For example if a client said it was 4 months before they first saw a health care provider, then in 23 the answer to the question should be at a minimum 4 months. We are asking for the longest time “ever” without seeing a health care provider, and not the time in between appointments.

For Q.24-34.

Q: If someone has already told you, in response to previous questions, that they have not seen a medical provider for their HIV in four years, can we skip these questions? They seem redundant.

A: No, for several reasons. First, the interviewer should not assume that an individual who has not seen a health care provider in several years has no regular place to go or no regular provider for their HIV care. We can only find out by asking the person. Second, we do not ask when the last time they saw a health care provider for their HIV – you might find this out through their story, or you might not. We want to ensure consistency of data collection. Therefore Q.24-27 must be asked unless the person has never seen a health care provider for HIV. However, if you already know the person has not seen a health care provider in over 6 months, asking Q. 28 can be awkward. Therefore, we suggest that you preface the question with, “I know you already mentioned this, but I need to ask the question again for the study.....” When you have confirmed that the answer is “0” you can skip to the missed appointment questions. Again, asking about missed appointments is important even if people haven’t seen a provider in many years, because we cannot assume they did not have any appointments scheduled in the past 6 months that they missed.

For Q. 28-30.

Q: How do we code the following case: A gentleman who didn't see an HIV provider specifically in the past 6 months, but was admitted to the hospital (6 times) where his blood was drawn for HIV and the results were discussed with him.

A: Enter 0 for question 28 (since he only went to the emergency room in the last 6 months) Enter N/A for questions 29 & 30. (In these questions we want to understand if the primary health care provider outside the ER or inpatient hospital visit had drawn the blood to check CD4 & viral load.)

For Q. 35.

Q: Are we interested in knowing if people are *taking* medications or if medications were *prescribed*?

A: we want to know if people are taking the medications. If not, they can tell us in the next question whether or not the drugs have been prescribed.

Q: do we want to know if people are taking medications consistently/adhering to their medications?

A: for the multi-site evaluation, no. This is not an adherence study, and we would need to do a lot more than ask a single question to determine adherence. Given the length of the interview, and the focus of this evaluation on outreach, engagement, and retention, the multi-site group decided not to ask about adherence for the multi-site evaluation. Adherence questions can be asked for the local evaluation if you want this information.

For Q. 37.

Q: Don't we want to know about prophylaxis in general, not just about PCP prophylaxis?

A: No. This was a subject of much debate by the multi-site group that developed this section of the interview. They were very divided between programs that operated out of clinics, had ready access to this information, and were involved in adherence studies, and the community-based outreach programs whose clients received medical care at multiple clinics and whose outreach efforts did not have any impact on the quality of HIV medical care individuals received once they got into care. This question represented a compromise between the two perspectives.

**Engagement with Provider section**

Please remember that if a client answers "NO" to 21 a (never saw a provider), you need to check off N/A for questions 39-53. This is not a stand-alone section. If in the course of the interview you learn the person has seen a medical provider at some point since testing positive, you will need to return to 21a and ask the questions (which were previously skipped) and then ask 39-53.

Q: If the person has not seen a health care provider in several years, can we skip this question?

A: No. Q. 39 asks if these responses refer to the person "who provides most of my care", or the "provider I last saw." It is possible that people who have not seen a health

care provider in several years will have very different responses to this question than people who are regularly engaged in care. And it is possible that people who become re-engaged in care may change their responses to this question over time. This is very important information to capture and if we do not ask the questions of people who have been out of care for a long time, we will not know the answers.

Q: if someone has not seen a provider in a long time, is it okay to use the past tense (e.g. “My provider listened to me”) rather than the present tense.

A: Yes.

### **Non-Medical Services: (Question 56 & 57)**

*General instructions:*

Remember to ask all the items under the “mandatory section.”

In the course of an interview, you may learn that a person is receiving certain services. When you ask question 56 “do you need the service..” client may respond “no because I’m receiving it. “ If they are receiving it, then 56 should be marked as yes and 57 should also be yes since they are getting the service.

However, if a client is receiving a service but feels they don’t need it, and they tell you this situation, then mark the answer for “do you need the service...” variable as “no.” For example, a person may respond that they have a case manager but they really don’t feel they need it. Then question 56 is marked as “no” and question 57 is N/A.

Our colleagues at Montefiore have provided suggested revisions to the instructions for interviewers to read to the client. Feel free to adopt these instructions if necessary:

#### **INTERVIEWER: Read the following.**

Some people receive all of the health and social services that they need, while others don’t receive their needed services. In order for us to help make services that people might want available to them, I am going to ask you about different kinds of services that you feel you might have needed in the past six months. First, please let me know which of the services you wanted, whether you received them or not. Will then ask if you were able to actually get the services you wanted.

#### *Specific Items*

For Q. 56. This is a long list of non-medical services and we ask people if they needed them in the past six months. If you know the person has no children, was born in the US, and/or speaks English as their primary language, then you may skip the relevant service (i, k, s) and code N/A.

For Q. 56.c Did you need *housing* over the last 6 months?

Q: People asked if this meant housing assistance or housing itself.

A: It means actual housing. In the subsequent questions (57, 58, 59) we want to know if they got housing, not if they got housing assistance. At the end of the day, people can get on dozens of waiting lists and fill out multiple applications, but still not have a stable place to live.

*Definition of Benefit/Entitlements:* (56h). Benefits/entitlements include: food stamps/vouchers, rental assistance, ADAP, SSI, Medicaid, and other federal/state/local government-funded programs that provide access to income or insurance. This will vary from each site. In some cases it may overlap with financial assistance. In general financial assistance means money to help pay bills, support income, etc. Check with your project directors or principal investigator if you are unsure which programs in your area are considered benefits or entitlements.

For Q. 57. Were you able to get this service in the last six months?

Q: The question was raised if we really meant – were you able to get this service from a service provider?

A: For now, the answer is no. The question stands as written – were you able to get this service? - as interpreted by the individual being interviewed, in whatever way they got the service. We can discuss at a later point if people want to interpret the question more narrowly. For example, if the client needed childcare, and their sister provided it, does that mean the client got the service? One suggestion is to probe in greater detail asking the client for a yes or no response: “So if your sister provided child care would you say “yes” you were able to get child care or “no”?”

Also if a client responds “somewhat” to Q 57 you may want to probe further. “What do you mean by somewhat able to get the service?” Would you say “yes” I got the service or “no” I didn’t get the service?” Then if yes, go to 59 to ask how much it has been resolved. If the client responds “no”- ask question 58 and then 59.

For Q. 59. How much has this problem been resolved? When asked about case management services, this can be confusing. We want to know if their ability to receive case management has been resolved.

### **III. Mental Health Section**

#### *Instructions for Mental Health Section*

Our colleagues at Montefiore have developed some instructions for introducing the mental health section of the survey to clients, and making the transition to these sensitive questions easier for interviewers and clients.

**INTERVIEWER: Read the following.**

This next section is about mental health or emotional problems that some people may have. I am going to ask you questions about seeing mental health providers and about taking medications for mental health or emotional problems. I realize these are sensitive issues, but remember that all of your answers are strictly confidential.

### **IV. Substance Use Section**

#### **Instructions for Substance Use Section**

Our colleagues at Montefiore have developed some instructions for introducing the substance use section of the survey to clients, and making the transition to these sensitive questions easier for interviewers and clients.

**INTERVIEWER: Read the following.**

This next section of the interview is about drugs and medications that some people use to get high. Many people have used or experimented with drugs at some time in their lives and I would like to know about your experiences. I’d like to remind you that all the information that you give us will be kept strictly confidential.

### Specific Questions

For Q. 66-68 ask about taking prescription drugs without a prescription.

Q: Some people asked if they could change the question to find out if people are taking these drugs – with a prescription – but abusing them.

A: No. This is a standardized instrument and the questions cannot be changed. The interviewer cannot infer abuse. The only thing that can be changed in these questions is to update the examples of drugs within certain classes to include more current drugs such as oxycontin (analgesic or painkiller).

For Q 80-105 ask if certain problems, beliefs, fears made it **difficult** to get HIV medical care.

Q: The question was asked if this meant that these problems, beliefs, and fears *prevented* the person from getting care.

A: No, this is about things that made it **difficult** to get care, which the person may or may not have ultimately received. In an earlier section of the interview, we ask about specific reasons why people missed specific appointments. In this section we want to know about things that made it difficult for people, but did not necessarily prevent them from getting care.

For Q. 87.

Q: Do we want to know what other problems people had getting an *appointment*, or getting *care* itself?

A: We want to know what other problems people had getting an *appointment*.

For Q77. If the individual says they are receiving methadone maintenance or buprenorphine, enter “d. Other,” and write in either “methadone maintenance” or “buprenorphine.”

For Q.79. We will provide an explanation of discrimination for you to use if the client is confused by this.

For Q. 88. You may change the verb “had” to “have.” (Were you afraid that other people might find out you have HIV if you went for care?).

### Definitions

For Q. 79 Discrimination. You can say: By discrimination, I mean have you been treated badly or differently because of your race, language, gender, sexual orientation, drug use or appearance when you went to get medical care.

For Q. 94: Unprotected sex: this refers to all types of sex: oral, anal or vaginal

Please feel free to contact CORE Carol Tobias ([tcaryl@bu.edu](mailto:tcaryl@bu.edu)) or Serena Rajabiun ([Rajabiun@bu.edu](mailto:Rajabiun@bu.edu)) tel (617) 426-4447 if during the course of your interviews there are additional questions or clarifications. Good Luck!!