# WOMEN'S INTERAGENCY HIV STUDY FOLLOW UP VISIT

# QUESTION BY QUESTION SPECIFICATIONS FORM 24: ALCOHOL, DRUG USE, AND SEXUAL BEHAVIOR

Guidelines for completing Form 24, "Alcohol, Drug Use and Sexual Behavior."

The Alcohol, Drug Use and Sexual Behavior Form will obtain information about the participant's drug history and sexual behaviors since her (MONTH) study visit. The WIHS is a study about HIV disease progression in women and as such does not collect information on *how* the participant became HIV infected. Rather, the focus in collecting data in Form 24 is to determine the impact of various risk factors/covariates on *HIV progression* in women.

## **General Instructions:**

1. Some questions in this form ask the participant to provide a specific number, such as, how many cigarettes she smoked or how many sexual partners she had. If the participant has difficulty giving a specific number, the interviewer should probe: "What is your best guess/estimate?" If the participant provides a range (for example, "20–30 male partners"), the interviewer should probe in such a way as to help the participant narrow it down (e.g., "within that range, which number comes closest?"). If after probing the participant is still unable to narrow down the response to one number, then record the lowest number in the range.

However, if the participant can provide the number of cigarettes she smoked or how many sexual partners she had <u>each week</u> or <u>each month</u>, the interviewer should calculate the total number of times since last visit based on the participant's response.

These probes and coding conventions should be used throughout Form 24 for any questions asking for a specific number.

2. All dates should be recorded in the MM/DD/YY format unless otherwise noted. For dates that must be completed on the form, if the participant cannot remember the exact month (or day), probe for the season. Use "15" for the day if the specific day cannot be recorded. Probe for the season and assign the month as follows:

Summer	=	July	=	07
Fall	=	October	=	10
Winter	=	January	=	01
Spring	=	April	=	04

Interviewers should have available an appropriate calendar to aid the participant in determining dates. Years in response to questions inquiring about occurrences "since last visit" should be 1995 and thereafter.

- 3. Times should be recorded in HH:MM format. Remember to use leading zeros, e.g., 08:00.
- 4. For questions containing an open-ended specify box linked to the response "other," interviewers should print responses exactly in the words of the respondent.
- 5. Obtain the date of the participant's previous visit from the Visit Control Sheet (VCS). This month should be used in the questions wherever (MONTH) appears.

Follow the skip patterns as they appear on the form.

### SECTION B: CIGARETTE AND ALCOHOL USE

B1. We want to learn about the participant's smoking history as it relates to her general health status and HIV progression. When reading this question, insert the date of the participant's

last visit that you recorded at question A6. Women who have not smoked since their (MONTH) study visit will skip questions B2–B4. If the participant has not smoked, skip to question **B5**.

- B2. If the participant has NOT quit smoking since her (MONTH) study visit, skip to question **B4**.
  - Record the month and the year when the participant quit smoking cigarettes. If she quit several times, probe for the most recent time she quit. Interviewers should have a calendar available to aid the participant in determining the date she guit smoking cigarettes.
  - Record the month and year (since her (MONTH) study visit) in which the participant resumed smoking after having quit. Interviewers should have a calendar available to aid the participant in determining the date she resumed smoking cigarettes. Interviewers should always skip to question **B4** after completing this question.
- B3. Record the average number of cigarettes the participant smoked each day before quitting. This number can refer either to packs (code 1) or individual cigarettes (code 2). If the participant gives an answer that involves halves (i.e., "half a pack" or "one and a half cigarettes" or "two and a half packs") the following conventions should be used:
  - PACKS may be reported using whole numbers only and must **not** be rounded. If the participant responds, "one and a half packs," you should convert that to the equivalent number of cigarettes and confirm with the participant. In this case, after converting one and a half packs to 30 cigarettes, the interviewer should confirm with the participant that she indeed smokes 30 cigarettes a day and then record "030" in the number field and circle code #2 (CIGARETTES).
  - You can and should round the number of CIGARETTES up to the nearest whole number. For example, if the participant says, "one and a half cigarettes," the interviewer should record "002" in the number field and circle code #2 (CIGARETTES).

NOTE: Many questions require the participant to provide an average amount or frequency. Some participants may have difficulty providing averages. (For example, the participant may not have smoked on a daily basis and the number of cigarettes may have varied when she did). The proper probe is to repeat the question emphasizing the words "average" and the time frame (e.g., "per day"). If after repeating the question the participant still cannot provide one number, continue probing to obtain a range. For example: "Can you give me a range of about how many?" Record the lowest number from that range in the space provided. The interviewer should not calculate averages for the participant. For example, if the participant states that she smoked 7–10 cigarettes on Saturday nights only, an **incorrect** probe would be: "So then would you say that you smoke one cigarette per day on average?"

> If after probing for a range the participant can still not give an answer, code the response as "DON'T KNOW" by recording "-8" (e.g., | | - | 8 |). Also write "DON'T KNOW" or "DK" in the margin to confirm that the data is missing.

Use the above probing instructions for all questions in this form which ask for an average number.

- B4. Record the average number of cigarettes the participant reports smoking each day. See instructions above regarding how to code ranges, halves, and "DON'T KNOW" responses.
- HAND PARTICIPANT RESPONSE CARD 9. The purpose of this question is to ascertain how B5. often the participant has a drink containing alcohol. If the participant responds that she drinks a type of alcohol that isn't specifically listed (e.g., "I drink jumbos. Does that count?"), then the interviewer should probe by encouraging the participant to state whether or not the drink is alcoholic (e.g., "Do jumbos have alcohol in them?"). Read the answer categories which appear in lower case aloud. It is very important that the participant hear all of the responses before selecting the choice that matches her frequency of alcohol use. If she has difficulty responding,

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encourage her to choose the category that generally comes closest to her situation (e.g., "Which choice is closest?").

If the participant did not drink alcohol (code 9) or declined to respond (code <-7>), skip to question C1.

- B6. The purpose of this question is to determine the average number of drinks the participant had on the days she drank. Read the answer categories which appear in lower case aloud. It is very important that the participant hear all of the responses before selecting the choice that matches her frequency of alcohol use. If she cannot give an exact answer, obtain a range and code the lowest number given.
- B7. The purpose of this question is to determine whether or not the participant's alcohol use affects her adherence to her HIV medications in her opinion. If the participant is HIV-negative or does not take ART, do not ask the question; circle response "3" and skip to **Section C**.
  - a. If the participant feels her alcohol use affects adherence to her HIV medications, record how she feels it is affected. Circle "YES" or "NO" for each response in i vi.

### **SECTION C: DRUG USE**

The purpose of these questions is to collect interim data about the participant's drug use as it relates to HIV progression (not transmission). This section may be highly sensitive for some women. Be sure to stress confidentiality.

A series of questions is asked for each substance the participant mentions having used/taken. The first question in the series serves as a qualifier. If the participant has *not* used the substance, the form instructs the interviewer to skip to the next substance. If the woman says that she has used that substance, the next questions obtain the general frequency of use, and whether or not use affects the participant's adherence to her HIV medications.

- C1. Ask about use of marijuana or hash since the participant's (MONTH) study visit.
  - a. This question inquires as to the participant's <u>average use</u> of marijuana or hash. As previously mentioned, averaging questions may be difficult for some women. USE PARTICIPANT RESPONSE CARD 10 throughout this section. Be sure to read the answer categories aloud the first time the subquestion is asked and again throughout this section as needed. When reading the question, stress the words *on average* and encourage the participant to select the choice that comes closest to describing her habits.
  - b-c This series of questions asks the participant why she used marijuana or hash on those occasions on which she used it. For each reason listed (i vi), circle "YES" or "NO," and if the response is "YES," ask how frequently she used marijuana or hash for that reason (subquestion c). If the response to subquestion b is "NO," skip to the next potential reason for use.
  - d. The purpose of this question is to determine whether or not the participant feels her marijuana or hash use affects adherence to her HIV medications. If the participant is HIV-negative or does not take ART, do not ask the question; circle response "3" and skip to question C2.
  - e. If the participant feels her marijuana or hash use affects adherence to her HIV medications, record how she feels it is affected. Circle "YES" or "NO" for each response.
- C2. Ask if participant has smoked crack since her (MONTH) study visit. If "NO," skip to question C3.
  - a. This question inquires as to how often the participant smokes crack on <u>average</u>. As previously mentioned, averaging questions may be difficult for some women. USE PARTICIPANT RESPONSE CARD 10 throughout this section. Be sure to read the answer categories aloud the first time the subquestion is asked and again throughout this section as

- needed. When reading the question, stress the words on average and encourage the participant to select the choice that comes closest to describing her habits.
- b. The purpose of this question is to determine whether or not the participant feels smoking crack affects her adherence to her HIV medications. If the participant is HIV-negative or does not take ART, do not ask the question; circle response "3" and skip to question C2.
- c. If the participant feels smoking crack affects her adherence to her HIV medications, record how she feels it is affected. Circle "YES" or "NO" for each response.
- C3. This series of questions is related to whether or not the participant has injected crack since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C4. This series of questions is related to whether or not the participant has sniffed or snorted cocaine since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C5. This series of questions is related to whether or not the participant has injected cocaine since her (MONTH) study visit. It is important the participant understands that this question refers to injecting cocaine by itself, and not cocaine mixed with heroin, which will be asked about later in the interview. Complete subquestions a through c as indicated for question C2.
- C6. This series of questions is related to whether or not the participant has sniffed or snorted heroin since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C7. This series of questions is related to whether or not the participant has smoked heroin since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C8. This series of questions is related to whether or not the participant has injected heroin since her (MONTH) study visit. It is important the participant understands this question refers to injecting heroin by itself, and not heroin mixed with cocaine, which will be asked about later in the interview. Complete subquestions a through c as indicated for question C2.
- C9. This series of questions is related to whether or not the participant has injected cocaine and heroin together (speedball) since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C10. This series of questions is related to whether or not the participant has sniffed or smoked methamphetamine (PROBE: crank, crystal, tina) since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C11. This series of questions is related to whether or not the participant has injected methamphetamine since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C12. This series of question refers specifically to use of methadone when it was not prescribed by a doctor. If the participant does not understand the question, repeat the question stressing the phrase when it was not prescribed to you by a doctor. The purpose of this question is to determine the frequency of illicit methadone use. Complete subquestions a through c as indicated for question C2.
  - d. The purpose of this question is to determine, in contrast to whether the participant's illicit methadone use affects her adherence to ART, whether or not her use of HIV medications affects how she takes methadone.
  - e. Record whether the use of HIV medications by the participant makes the participant need to use more or less methadone.

- C13. This series of questions is related to whether or not the participant has used amphetamines since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C14. This series of questions is related to whether or not the participant has used hallucinogens (e.g., LSD, PCP, mushrooms, peyote) since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C15. This series of questions is related to whether or not the participant has used any club drugs (such as ecstasy, ketamine, GHB) since her 9MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C16. This series of questions is related to whether or not the participant has used any other narcotic drugs, such as morphine, codeine, oxycodone or Demoral, when they were not prescribed by a doctor, since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C17. This series of questions is related to whether or not the participant has used any tranquilizers, such as sleeping pills, barbiturates or valium, whether or not they were prescribed by a doctor, since her (MONTH) study visit. Complete subquestions a through c as indicated for question C2.
- C18. Based on the participant's responses to questions C3 (injected crack), C5 (injected cocaine), C8 (injected heroin), C9 (injected speedball) and C11 (injected methamphetamine), indicate whether or not she has injected any drugs since her (MONTH) study visit. If "NO," skip to **Section D**.
  - The purpose of the next series of questions is to obtain information that will enable WIHS investigators to look at how drug injection relates to HIV progression. These data will not be used for tracking HIV transmission. These questions may be highly sensitive to some women. If the participant becomes defensive, reassure her that her answers are strictly confidential.
- C19. We would like to know the total number of times the participant injected drugs of <u>any kind</u> since her (MONTH) study visit. This question sounds similar to several of the questions previously asked, but is different in that it pertains to the <u>total number</u> of times the participant injected any kind of drug.
  - a. We would like to know if the participant injected drugs in a shooting gallery. Interviewers should not attempt to define "shooting gallery." If the participant asks what that term means, an appropriate response would be, "Please answer as best you can based on what it means to you."
- C20. We would like to know how many times <u>over the past month</u> (rather than since her last study visit) the participant injected drugs. It is important that the participant understand the time frame. If the participant has trouble coming up with a number, you may use the probe provided in parentheses immediately after this question. If the participant still cannot give an answer, the interviewer should probe for a range and record the lowest number from the range given. If the participant can provide the number of times she injected drugs each day or each week, the interviewer should calculate the total number of times she injected drugs over the past month based on the participant's response.
- C21–C23 This series of question refers to using injection equipment (needles, syringes, cookers, cottons, rinse water) <u>after someone else has used them</u>. A cooker refers to a bottle cap, or other metal holder, used for heating the drugs. The possibility of exposure to various bacteria and viruses exists when water is shared.

For each item, ask the participant how often she has used the specified injection equipment when she is **absolutely sure** it has not been used by anyone else first.

C24–C26 This series of questions refers to the participant using injection equipment (needles, syringes, cookers, cottons, rinse water) before someone else uses them. For each item, ask the participant how often someone else has used the injection equipment when it was first used by the participant.

## PROMPT: FOR ALL SHADED RESPONSES IN SECTION C, REFER PARTICIPANT TO THE APPROPRIATE COUNSELOR.

- C27. The purpose of this question is to determine if the participant has cleaned her works with bleach since her (MONTH) study visit. Again, information obtained from this question will be used to look at how particular behaviors relate to HIV progression. This may also be a sensitive question. Reassure the participant of confidentiality.
- C28. The purpose of this question is to find out if the participant has received clean needles from a needle exchange program. If the woman responds that she has applied to a program but is waiting for a response or that she is on a waiting list, repeat the question stressing the word "participated." We are interested in knowing if she actually received clean needles.
  - a. This question is asked to determine, how often—of all the times the participant obtained needles—she obtained them from a needle exchange. Read the question and each response choice. It is very important that the participant hear all of the response categories before selecting her choice. If she has difficulty responding, use probes which encourage her to choose the answer that comes closest to her habits.

### **SECTIONS D-E: SEXUAL BEHAVIOR**

Sections D and E are used to obtain information about the participant's sexual risk behavior patterns since her (MONTH) study visit. Questions about the participant's sexual history are asked in order to obtain a measure of the degree to which the participant engages in high-risk sexual behaviors that may be associated with exposure to HIV and other sexually transmitted diseases (STDs).

#### **SECTION D: MALE PARTNERS**

INTRODUCTION: The introduction reminds participants that we are interested in <u>all</u> sexual activity with men, including prostitution or sex in exchange for money, drugs, or shelter. These questions may be highly sensitive. Be sure to ask each question in a professional, matter-of-fact, non-judgmental tone.

Questions D1 refers to sexual practices with <u>all</u> male partners since the participant's (MONTH) study visit. The words "including men or boys" may be used as a probe to ensure that participants include <u>all</u> males regardless of age. If a participant reports more than 5 sexual partners in D1, questions D3-D10 should be asked of the 5 most recent partners.

D1. This question will obtain information for use in assessing the participant's sexual risk behaviors. We want to know how many different <u>males</u> (including her main partner) the participant had sex with since her (MONTH) study visit. The probe "including men or boys" may be used as clarification. The word "partner" has purposely not been used in this question to ensure that the participant includes all males with whom she has had a sexual encounter of any kind, with or without consent.

The following probes explain what is meant by "sex" should be used if the participant indicates confusion or difficulty in answering this question. For the purpose of these questions, "sex" includes vaginal sex, both types of oral sex, and anal sex.

- vaginal sex when a man puts his penis in your vagina
- <u>oral sex</u> when a man puts his penis in your mouth and/or when a man puts his tongue in or on your vagina
- <u>anal sex</u> when a man puts his penis in your rectum (butt/bottom/ass)

Record the number using leading zeros. For example: *three men* should be recorded as "003." If the participant declines to give a number, code the response as "DECLINED" by recording a "-7" in the field  $[ | \_ | - | 7 | ]$  and writing "DECLINED" or "DECL" next to the field as a confirmation of the missing data. If the participant indicates that she has not had sex with any males or declines to answer, skip to question E1.

If the participant says that she doesn't know, you may need to probe (e.g., "Could you give me your best estimate?"). If, after probing non-directively, the participant still cannot give an exact number, obtain a range (e.g., "Can you estimate by giving me a range?") Record the lowest number from the range given. For example: If the participant says, "I don't know... more than 10," then you would record "010." Similarly, if the participant says, "Between 11 and 15," record "011." If the participant can provide the number of different men with whom she had sex each week or each month, the interviewer should calculate the total number of men based on the participant's response.

If, after probing, the participant still cannot give a number, code the response as "DON'T KNOW" by recording a "-8" in the field and writing "DON'T KNOW" or "DK" beside the field to confirm the missing data. Read the PROMPT in the box and proceed to question D2 (if the participant has had sex with a male).

If the participant reports more than 999 partners, record "999" and confirm that number by writing it in the margin next to the field. If the participant answers "NONE," record "000" and skip to **question E1.** 

- D2: This question asks the participant for a nickname, initials, or some other name to identify each of the partners that she has reported in question D1. The participant is **NOT** to give the real name for each of her partners. Instruct her to begin with the most recent partner. If she reports more than 5 partners in question D1, only list the 5 most recent partners. Probe for more information after identification of the partners reported in D1. Ask her if there are any other partners that she can think of since her last (MONTH) study visit. Remind her that "sex" includes vaginal sex, both types of oral sex, and anal sex. If the numbers reported in D1 and D2 do not agree, clarify with participant and modify answers as needed. Again, if there are more than 5 partners for question D1, question D2 should only include the 5 most recent partners.
- D3a. For D3a, the <u>number</u> associated with the initials or nickname should be entered. For example, if the participant reports "MS" for PARTNER ID 1, and "JD" for PARTNER ID 2, a "1" should be entered in D3a when asking about "MS" and a "2" should be entered when asking about "JD."
- D3-D10. Questions D3-D10 should then be asked for each partner listed in D2.

**NOTE**: For question **D5b**, we are interested in knowing if any type of condom was used during vaginal sex with that particular partner. This means that if either a male or female condom was used with this partner, the participant should answer yes to this question.

### **SECTION E: FEMALE PARTNERS**

Question E1 refers to sexual practices with **all** female partners since the participant's (MONTH) study visit. The words "including women or girls" may be used as a probe to ensure that participants include **all** females regardless of age.

E1. This question will obtain information for use in assessing the participant's sexual risk behaviors. We want to know how many different females (altogether, including her main partner) the participant had sex with since her (MONTH) study visit. The probe "including women or girls" may be used as clarification. The word "partner" has purposely not been used in this question to ensure that the participant includes all females with whom she had a sexual encounter of any kind, with or without consent.

The following probes explain what is meant by "sex" should be used if the participant indicates confusion or difficulty in answering this question. For the purpose of these questions, "sex" includes vaginal sex, oral sex, and anal sex.

- <u>vaginal sex</u> when a woman puts fingers, fists, sex toys, dildos or vibrators around or in your vagina
- <u>oral sex</u> when a woman puts her tongue or mouth in or on your vagina and/or when you put your tongue or mouth in or on another woman's vagina
- <u>anal sex</u> when a woman puts fingers, fists, tongue, sex toys, dildos or vibrators in your rectum (butt/bottom/ass)

Record the number using leading zeros. For example: *three women* should be recorded as "003." If the participant declines to give a number, code the response as "DECLINED" by recording a "-7" in the field  $[ | \_ | - | 7 | ]$  and writing "DECLINED" or "DECL" next to the field as a confirmation of the missing data. If the participant indicates that she has not had sex with any females or declines to answer, skip to question F1.

If the participant says that she doesn't know, you may need to probe (e.g., "Could you give me your best estimate?") If, after probing non-directively, the participant still cannot give an exact number, obtain a range (e.g., "Can you estimate by giving me a range?") Record the lowest number from the range given. For example: If the participant says, "I don't know... more than three," then you would record "003." Similarly, if the participant says, "Between eight and ten," record "008." If the participant can provide the number of different women with whom she had sex each week or each month, the interviewer should calculate the total number of women based on the participant's response.

If, after probing, the participant still cannot give **any** response at all, code the response as "DON'T KNOW" by recording a "-8" in the field and writing "DON'T KNOW" or "DK" beside the field to confirm the missing data.

If the participant reports more than 999 partners, record "999" and write the actual number in the margin next to the field. If the participant answers "NONE," record "000" and skip to question F1. However, if the response at D1=000 and at E1=000, skip to question F3.

### **SECTION F: RECENT SEXUAL ENCOUNTERS**

If the participant reports having no sex with either males (D1 = 000) or females (E1 = 000) since her (MONTH) study visit, skip to question F3.

F1. We would like to know whether the participant has received drugs, money or shelter from anyone (male or female) in exchange for having <u>any type of sex</u> since her (MONTH) study visit. (If necessary, read the definitions of sex given in the QxQs for questions D1 and/or E1.) If the participant responds she has never had sex for drugs or money or shelter, skip to question F3.

- F1b. We would like to know how many times the participant had sex for drugs since her (MONTH) study visit. If the participant cannot give an exact number, probe for a range by saying, "Can you estimate by giving me a range?" Record the lowest number from the range given. If the participant can provide the number of times she had sex for drugs each week or each month, the interviewer should calculate the total number of times since her (MONTH) study visit based on the participant's response.
- F3. Record the actual time you completed administering the module. Remember to use leading zeros. For example: 08:00 AM; or 06:00 PM. Circle the code for AM (1) or PM (2).