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. Use the form version dated 10/01/03.
- 2. Many questions in this form ask the participant to provide a specific number, such as, how many cigarettes she smoked, the number of times she used cocaine, 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, the number of times she used cocaine, or how many sexual partners she had each week or each month, 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.

3. 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.

- 4. Times should be recorded in HH:MM format. Remember to use leading zeros, e.g., 08:00.
- 5. For questions containing an open-ended specify box linked to the response "other," interviewers should print responses exactly in the words of the respondent.
- 6. 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 be skipped out of 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**.
 - a. 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 quit smoking cigarettes.
 - c. 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 <u>up to the nearest whole number</u>. 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).

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 only smoked 7–10 cigarettes on Saturday nights, 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., $|\underline{}|\underline{}-\underline{}\underline{}|$). 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.
- B5. HAND PARTICIPANT RESPONSE CARD 9. The purpose of this question is to ascertain *how 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, 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.

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 second question obtains the general frequency of use. These questions are formatted in a chart containing rows and columns. Begin in the first row and proceed left to right across the columns. Some subquestions do not apply to a particular substance. In such cases the subquestion will be shaded and the interviewer should proceed to the next row.

Subquestion "a" (middle column, C1–C7):

This question inquires as to the participant's <u>average use</u> of the substance listed in that particular row. 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.

Subquestion "b" (right column, C1-C6):

This question inquires as to the <u>total number of times</u> the participant has used the substance listed in that row. If the participant cannot give an exact number, you may use the probe that appears at the bottom of page 4 and intermittently throughout this section (i.e., "In a sixmonth time frame, for example, once a day equals 180 times, once a week equals 25 times, and once a month equals 6 times.") If you have probed and the participant still cannot give an answer, you may probe to obtain a range of numbers (e.g., "Can you give me a range of about how many times?"). Record the lowest number of the range given in the space provided. If the participant can provide the number of times she used a particular drug each week or each month, the interviewer should calculate the total number of times since her last study visit based on the participant's response.

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

If the participant reports using a drug more than 999 times since her last visit, record "999" and confirm that number by writing it in the margin next to the field.

- C2. This question refers specifically to use of methadone when it was not prescribed by a doctor. (Formally, supervised methadone treatment programs will be addressed later in this form.) 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.
- C3. Question C3 refers to three different drugs: crack, cocaine, and heroin. Read the question exactly as worded and don't omit any words. Since obtaining information about the use of these drugs is sensitive, we want to minimize the number of questions asked of the participant. If the participant has not used any of the listed drugs, skip to question C7.
- C5. It is important to note that this type of cocaine does <u>not</u> refer to cocaine in the form of crack. Use of *crack* should be noted at question C4.
 - c. The table formatting of questions is interrupted at this question (and at questions C6c and C6d as well). This question, regarding the use of cocaine by snorting, should only be asked of participants who reported having used cocaine at question C5. If the participant answers "NO," skip to question C6. If the participant has used cocaine by snorting, ask subquestion "i" (i.e., "How many times?"). This question may seem repetitive because it is similar to subquestion "b." If the participant says something to this effect, clarify that you are interested specifically in snorted cocaine.
- C6c. This question may seem repetitive because it is similar to subquestion "b." If the participant says something to this effect, clarify that you are interested specifically in snorted heroin.
- C6d. This question may seem repetitive because it is similar to subquestions "b" and "c." If the participant says something to this effect, clarify that you are interested specifically in <u>smoked</u> heroin.
- C7. The purpose of this question is to ascertain the use of amphetamines and/or <u>any other drugs</u> not previously mentioned by the interviewer. This question includes several substances that fall into the category of "other drugs." There are many drugs that may be mentioned that do not appear on the list. We are interested in anything the participant states she used. If the participant is unsure about a drug, read the sentence again, along with the probe in parentheses. If she mentions a drug she is unsure whether to include (e.g., drug "XYZ"), an appropriate probe would be, "Do you consider XYZ a drug?" You, as the interviewer, should

- not decide whether what the participant used is a drug; instead, encourage the participant to make that judgment herself.
- a. See QxQ instructions for subquestion "a." If the participant has used several "other" drugs, ask her for the average frequency of her use of "all the other" drugs, since her (MONTH) study visit.
- C8. The purpose of this question is to obtain information that will enable WIHS investigators to look at how drug injection relates to HIV progression. This data will not be used for tracking HIV transmission. We would like to know if the participant has injected drugs of any kind since her (MONTH) study visit. This question may be highly sensitive to some women. If the participant becomes defensive, reassure her that a simple "YES" or "NO" response is all you need and that her answers are strictly confidential. NOTE: Alternative phrases in parentheses have been provided if the participant has difficulty understanding the term *injection*. If the response is "NO," skip to question C12.
 - 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."
 - b. We would like to know how many times the participant injected a speedball. The definition of speedball, "heroin and cocaine together," is in parentheses and can be read if the participant is unclear as to its definition.
 - c. We would like to know how many times the participant injected cocaine by itself. It is important the participant understands this question refers to cocaine by itself and <u>not</u> cocaine mixed with heroin, which was asked about in the previous question.
 - d. We would like to know how many times the participant injected heroin (by itself). It is important the participant understand this refers to heroin by itself and <u>not</u> heroin mixed with cocaine, which was asked about in subquestion "b."
 - e. We would like to know how many times the participant injected speed or crank (by itself). It is important the participant understand this refers to crank by itself and <u>not</u> mixed with anything else.
 - f. We would like to know the total number of times the participant injected drugs of <u>any kind</u>. This question sounds similar to several of the questions previously asked, but is different in that it pertains to the <u>total</u> number of times the participant injected <u>any</u> drug.
 - g. We would like to know how many times over the past month (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 subquestion. 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.
- C9. This question refers to sharing needles or works when injecting drugs. The term "works" is defined as part of the question and should be read aloud. A cooker refers to a bottle cap, or other metal holder, used for heating the drugs. This question will provide information on how drug injection relates to the progression of HIV. Note that it is not important whether the participant has used the needles *before* or *after* another person, since that information will be collected in the subsequent series of questions. At question C9 we simply want to know if she has shared needles or works with anyone. This question, like others, may be highly sensitive.

- Reassure the woman that she need only respond "YES" or "NO" and that her answers are confidential.
- a. We would like to know how many times the participant has used needles that were already used by someone else and then passed on to her. If the participant has difficulty providing an exact number, the interviewer may use the probe printed in parentheses on the previous page (i.e., "In a six month time frame, for example, once a day equals 180 times, once a week equals 25 times, and once a month equals 6 times"). If the participant still cannot give a number, probe for a range and record the lowest number given. If the participant can provide the number of times she used needles that were already used each week or each month, the interviewer should calculate the total number of times based on the participant's response.
- b. We would like to know the number of different people with whom the participant has shared previously used needles. It is important that the participant understands this question refers to different people (as opposed to episodes). For example, if she shares her works with only her boyfriend on a daily basis, the correct response is one person. If she shares her works with a group of people (even just once) then each person in the group should be included in her count. Again, this may be a sensitive question and the participant may need to be reassured of the confidentiality of what she is telling you. If the participant cannot give an exact answer, probe for a range and record the lowest number.
- c. This question is asked to determine if the participant shared water to rinse her needles with anyone. This information will be used to investigate HIV progression in women. The possibility of exposure to various bacteria and viruses exists when water is shared. Again, this may be a sensitive question. Reassure the participant of confidentiality. If the participant responds "NO," skip to question C10.
- e. We would like to know the number of <u>different people</u> with whom the participant has shared water to rinse needles. Again, be sure the participant is aware this question refers to the number of <u>different people</u> (refer to question C9b for further explanation). If the participant cannot give an exact answer, probe for a range and record the lowest number.
- C10. The purpose of this question is to determine how often the participant cleaned her works with bleach. "Works" is defined in parentheses. 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. 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.
- C11. 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.

C12, C15. The purpose of these questions is to determine use of Rave drugs since last visit. Ask the participant each question as written. If she is not familiar with the drug name given, read the text in parentheses containing other well known names for that drug.

If the participant reports use of any of these drugs since her (MONTH) study visit, she should be referred to the appropriate counselor.

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
- anal sex 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 <u>each</u> 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.
- F2, F2a-d: Questions deleted.
- 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).