

WOMEN'S INTERAGENCY HIV STUDY
QUESTION-BY-QUESTION SPECIFICATIONS
FORM 20: NEW RECRUIT BASELINE HISTORY

The *New Recruit Baseline History Form* is a supplemental form to be administered to the new recruits enrolled during the expansion project. This form is a compilation of various questions from the following forms: *F21 (Sociodemographics)*, *F22HX/MED (Health and Medication Use History)*, *F23 (Obstetric, Gynecological and Contraceptive History)*, and *F24BEH (Alcohol, Drug Use and Sexual Behavior)*. The purpose of this form is to obtain each participant's history up to the present. This is in contrast to the current follow-up forms, which, for new recruits, will refer only to the six months preceding the participant's baseline visit.

Some of these questions may be difficult for the participants to answer. Stress to the participant that her responses are strictly confidential and will not be associated with her name or identity in any way. They will be used only for WIHS research purposes.

SECTION A. GENERAL INFORMATION

Read the introduction to the participant.

SECTION B. SOCIODEMOGRAPHIC DATA

- B1-B3. Questions regarding bilingualism will be added to the baseline interview beginning with visit 37.
- B4. Record the highest grade or year of school that the participant has completed.
- B5. Record the highest grade or year of school that the participant's mother has completed.
- B6. Ask if the participant has received a blood transfusion between the years 1975 and 1985.
- B7. Ask if the participant has ever been incarcerated or spent time in prison or jail. If the participant answers "NO," skip to **Section C**.
- a. Indicate the total number of times the participant has been incarcerated in her lifetime.
- b. Indicate the total number of months the participant has been incarcerated in her lifetime. For any portion of a month less than 15 days, record as "0." For any portion of a month 16 days or greater, record as "1."

SECTION C. MEDICAL AND HEALTH HISTORY

NOTE: The questions asked in **Section C** are asked of both seropositive and seronegative women. Some of these questions refer to HIV infection and AIDS-related conditions. Some women may become worried or upset while being administered this section. You may want to say something such as: "***I need to ask these questions of everyone who is enrolled in this study.***"

READ THE INTRODUCTION TO SECTION C.

- C1. a. Indicate if the participant remembers ever being told by a health care provider (doctor, nurse, physician's assistant or nurse practitioner) that she had cervical cancer. Skip to **Question C2** if the participant answers "NO."
- b. Record the year that the participant was first told she had cervical cancer.
- c. Record whether the participant has ever had surgery to treat cervical cancer. **PROBE: *Been admitted to the hospital and had surgery in an operating room.***
- d. Record whether the participant has ever had a CAT or MRI scan of her abdomen. **PROBE: *A big donut-shaped machine that takes special pictures.***

- e. Record whether the participant has ever been told that she needs either surgery or radiation therapy.
- C2. Indicate if the participant remembers ever being told by a health care provider that she had any other type of cancer besides cervical cancer. This includes any kind of cancer (such as skin cancer, breast cancer, ovarian cancer, etc.). Skip to **Question C12** if the participant answers “NO.”
- C3. Ask the participant if she was ever told she has breast cancer. If she answers “NO,” skip to **Question C4**. If “YES,” ask questions C3a through C3c.
- a. Record the year that the participant was first told she had breast cancer.
 - b. Ask the participant if she has ever had a lump removed from her breast by a surgeon. **PROBE: *Not a needle biopsy, but an incision resulting in stitches.***
 - c. Ask the participant if she has ever had a mastectomy. **PROBE: *Removal of entire breast.***
- C4–C12. Ask the participant whether or not she has ever been told she has each kind of cancer as listed in **Questions C4** through **C12**.
- a. Record the year that the participant was first told she had each kind of cancer reported in **Questions C4** through **C12**.
- C13. In **Question C13**, the interviewer should record the total number of cancers self-reported by the participant. Make sure to include cervical cancer if reported in **Question C1a**, as well as all cancers reported in **Questions C3** through **C12**. This question should not be read aloud to the participant.

PROMPT: IF QUESTION C13 = 00, SKIP TO QUESTION C18.

PROMPT: FOR EACH CANCER INDICATED IN QUESTION C13, COMPLETE QUESTIONS C14 AND C15. THE NUMBER OF BOXES COMPLETED MUST EQUAL THE VALUE RECORDED AT C13. INDICATE THE LOCATION OF EACH REPORTED CANCER IN a, THEN COMPLETE b THROUGH f AS INDICATED FOR EACH. IF THE TOTAL NUMBER OF REPORTED CANCERS IS GREATER THAN TWO, PLEASE XEROX THIS PAGE AND INSERT THE COPY AFTER PAGE 5.

- C14–C15. These questions are to be completed if the participant reports any cancer diagnoses in **Question C1a** or in any of **Questions C3** through **C12**. The questions are asked in order to determine whether or not the participant has been diagnosed with metastatic cancer, and, if so, to obtain details about its spread.
- a. Record the location of each reported cancer on this line. Do not ask the participant this question; just transfer the cancer diagnosis location from each of **Questions C1a** and **C3** through **C12** that she answered affirmatively. In **Questions C14** and **C15**, whenever you see (LOCATION) in a question, replace it with the location of the cancer diagnosis recorded in **Question a**.

PROMPT: REPLACE (LOCATION) WITH THE LOCATION WRITTEN IN C14a/C15a.

- b. If this was the participant’s first diagnosis of cancer, proceed to **Question c**; if not, skip to **Question e**.
- c. If the participant was told that this cancer had metastasized to another part of her body, proceed to **Question d**; if not, skip to **Question C15** if she reported another cancer diagnosis in **Questions C1a** and **C3** through **C12**, or to **Question C16** if she reported no other cancer diagnoses.
- d. Record to where the participant’s cancer has spread, and then skip to **Question C15** if she reported another cancer diagnosis in **Questions C1a** and **C3** through **C12**, or to **Question C16** if she reported no other cancer diagnoses.

- e. This question will only be asked if the participant indicates that she had received a prior cancer diagnosis. Indicate if the new cancer that the participant is now reporting had metastasized from her original cancer. Proceed to **Question f** regardless of whether she responds yes or no.
- f. Record the location of the original cancer. Proceed to **Question C15** if she reported another cancer diagnosis in **Questions C1a** and **C3** through **C12**, or skip to **Question C16** if she reported no other cancer diagnoses.

PROMPT: IF ANY OF QUESTIONS C1 THROUGH C12 = YES, THEN COMPLETE ASCERTAINMENT TRACKING CHECKLIST (ATC) FOR EACH ILLNESS AND OBTAIN MEDICAL RECORD RELEASE. ALSO, IF EITHER OF QUESTIONS C14c/C15c OR C14e/C15e = YES, THEN COMPLETE ATC FOR METASTATIC CANCER.

- C16. Indicate if the participant has ever received cancer chemotherapies. Do not explain further.
- C17. Indicate if the participant has ever received radiation treatments. Do not explain further.
- C18. We want to know if the participant has ever had asthma. For the study, reports of this condition DO NOT require diagnosis by a health care provider (doctor, nurse, nurse practitioner or physician’s assistant). Skip to **Question C19** if the participant answers “NO.” If the participant answers “YES,” ask **Question a**.
 - a. We want to know approximately how many years ago the participant's asthma began. **PROBE: Please remember as best you can.**
- C19. Indicate if the participant has ever taken a medication to prevent getting TB. **PROBE: Usually this kind of medicine is given after a positive reaction to a TB blood or skin test.** If the participant responds “NO,” skip to **Question C20**.
 - a. Record the year in which the participant started taking medication to prevent getting TB.
 - b. Record the number of pills taken per day to prevent TB.
 - c. Indicate for how long the participant took medication to prevent TB.
 - d. Indicate if the participant was in an institution, such as a nursing home, recovery home, or prison, when she took medication to prevent TB.
- C20a–f. This study is about the progression of HIV disease in women and we want to know if the women who participate in this study have any other illnesses or conditions. We want to evaluate the progression of disease in women and it would be important to take into consideration the effect that other illnesses may have in relation to HIV disease. These questions ask about conditions that require or required medical care. If the participant does not recognize the medical terminology, circle “2” (NO). DO NOT LEAVE ANY BLANK.
 - a. We want to know if the participant remembers ever having high blood pressure or hypertension (**PROBE: blood pressure that is above the normal range**) that required medical care.
 - b. We want to know if the participant remembers ever having high blood sugar or diabetes that required medical care. Do not define further.
 - c. We want to know if the participant remembers ever having any rheumatologic disease, including rheumatoid arthritis or lupus, that required medical care.
 - d. We want to know if the participant remembers having an operation to remove the spleen. **PROBE: A splenectomy.**
 - e. We want to know if the participant remembers having a sinus infection that required antibiotics. Circle “1” (YES) if participant reports a sinus infection that was treated with antibiotics.

- f. We want to know if the participant remembers ever having a urinary tract infection (e.g., bladder/UTI, kidneys/pyelonephritis, urethritis) that required treatment with antibiotics.
- C21. We want to know if the participant has ever taken medication or been hospitalized for depression.
- C22. We want to know if the participant has ever been told by a health care provider that she had hepatitis C. If response is “NO,” skip to **Question C24.**
- C23. Indicate if anyone has ever offered the participant treatment for hepatitis C.
- Indicate if the participant agreed to be treated for hepatitis C. If response is “NO,” skip to **Question C24.**
 - Record the year the participant started treatment for hepatitis C. If the participant has received treatment for hepatitis C more than once, record the year for the most recent time she started treatment.
 - Indicate if the participant is currently in treatment for hepatitis C. If response is “YES,” skip to **Question C24.**
 - Record the year the participant stopped treatment for hepatitis C. If the participant has received treatment for hepatitis C more than once, record the year for the most recent time she stopped treatment.
- C24a. Record the hepatitis **B** and **C** medications used by the participant. Hand the participant the current version of the **Response Card D4a** and go through the card with the participant, asking for each medication, “*Since your (MONTH) study visit, have you taken (DRUG NAME)?*” For all participants using hepatitis medications, mark each drug the participant has ever taken by placing an “X” in the corresponding box. If participant has used a hepatitis medication that is not listed on the form, specify the medication(s) taken in the box provided and enter the appropriate drug code.
- Circle the appropriate response to indicate if the participant has not taken any hepatitis medications or has taken at least one hepatitis medication. If she has taken none, skip to **Question C25.**
 - Enter the total number of hepatitis medications the participant reported taking in **Question C24a.**
- C25. Indicate if the participant has ever been told by a health care provider that she needed a liver transplant. If response is “NO,” skip to **Question C28.**
- C26. Indicate if the participant has ever had a liver transplant. If response is “NO,” skip to **Question C27.**
- Record the year in which the participant had a liver transplant.
- C27. Indicate if the participant is currently on the waiting list for a liver transplant.
- C28. Indicate if the participant has ever been told by a health care provider that she had osteopenia or osteoporosis or low bone mineral density. **PROBE: *That is, thinning or weakening bones.***
- C29a–c. Indicate if the participant has ever been told by a health care provider that she had broken or fractured her hip (**Question a**), wrist (not including forearm or hand) (**Question b**), or spine (**Question c**).
- For each fracture, record the participant’s age at the time of the broken bone. If the participant has broken any bone multiple times, enter the participant’s age at the time of the most recent fracture.
 - For each fracture, indicate how the fracture occurred. If the participant has broken any bone multiple times, enter how the fracture occurred for the most recent fracture.

- C30. Indicate if the participant has ever had a serious head injury. **PROBE: A serious head injury may be associated with dizziness, confusion, pain that lasts after the injury, a loss of consciousness, or needing a hospital visit.** If response is “NO,” skip to **Question C32.**
- a. Record the number of head injuries the participant reports having in her lifetime.

PROMPT: FOR EACH HEAD INJURY INDICATED IN QUESTION C30a, COMPLETE QUESTIONS C31a to C31g. THE NUMBER OF SUBFORMS COMPLETED MUST EQUAL THE VALUE RECORDED AT QUESTION C30a. IF THE TOTAL NUMBER OF REPORTED HEAD INJURIES IS GREATER THAN ONE, PLEASE XEROX THIS PAGE AND INSERT THE COPY AFTER PAGE 10.

- C31a. Indicate how the head injury occurred.
- b. Record the participant’s age at the time of the head injury.
 - c. Indicate if the participant saw a doctor because of the head injury.
 - d. Indicate if the participant stayed overnight in a hospital because of the head injury.
 - e. Indicate whether or not the participant lost consciousness (**PROBE: were “knocked out”**) due to the head injury. If response is “NO,” skip to **Question f.** If response is “YES,” ask the participant how long she was unconscious and record her response in number of minutes, hours or days in **Question i.**
 - f. Indicate whether the participant had a skull fracture.
 - g. Indicate whether the participant had a seizure or fit within seven days after the head injury.

- C32a–d. **NOTE: The definition of healthcare provider changes in this section and now includes dentists.**

We want to know if the participant remembers ever being told by a health care provider (doctor, dentist, nurse, nurse practitioner or physician’s assistant) that she had the conditions listed in **Questions C32a through d.** The words listed in the form in parentheses may be read to the participant to clarify the condition. To avoid biasing the interview, do not define further. Circle “1” (YES) only if diagnosed in those words by a health care provider (doctor, dentist, nurse, nurse practitioner or physician’s assistant).

- C33. We want to know if the participant was ever told by a health care provider that her CD4 count was less than 200 or less than 14%.

- C34. Indicate whether or not the participant reports having ever had a biopsy. **PROBE: A biopsy is when tissue, sometimes a lump or a mass, is removed with a needle or by making an incision.** If response is “NO,” skip to **Question C35.**

- a–h. Indicate where in the body the participant reports having had a biopsy.

- C35. We want to know if the participant remembers any other major illness, excluding HIV infection that required or requires medical care and that has not been asked about up to this point in the interview. These other illnesses may include any surgery that she may report here and/or any psychiatric diagnoses. If the participant answers “YES,” ask her to specify and record her response(s) verbatim on the lines provided.

- C36. Indicate if the participant has ever received any of the vaccinations listed in **Questions a through h.** If “YES,” ask the year in which she received each vaccination for the most recent time.

SECTION D. OBSTETRIC, GYNECOLOGICAL AND CONTRACEPTIVE HISTORY

- D1. We are interested in knowing if the participant has ever been pregnant. If the participant answers “NO,” skip to **Question D12**.
- D2. Indicate if the participant is currently pregnant.
- D3. We would like to know the number of times the participant has been pregnant in her lifetime, excluding any current pregnancy. Enter the number of confirmed pregnancies the participant has reported. **PROBE: Please include all pregnancies regardless of outcome. Do not include your current pregnancy.**
- D4-D10. Hand the participant **Response Card 8**. For these questions, it is important to read all the categories the first time you ask **Question a**. The interviewer does not need to read the categories for the following pregnancies unless the participant has difficulty remembering all the choices.

We would like to know the outcome of each pregnancy and the month and year when it occurred. These questions record the number of live births, multiple births, miscarriages, therapeutic or elective abortions, stillbirths and tubal pregnancies that a woman has had in her lifetime.

PREGNANCY OUTCOME DEFINITIONS:

- **Live birth:** By live birth we mean a baby that was born alive.
 - **Stillbirth:** By stillbirth we mean a baby that was born dead.
 - **Abortion:** By abortion we mean a pregnancy in which the participant chose to end the pregnancy, and did so by having a procedure performed.
 - **Miscarriage:** By miscarriage we mean a pregnancy where the participant lost the baby before she was 20 weeks, or five months, pregnant.
 - **Ectopic Pregnancy:** By ectopic pregnancy we mean a tubal pregnancy that occurred in the woman's fallopian tubes.
- a. If the pregnancy outcome is coded as “abortion,” “miscarriage,” “ectopic pregnancy,” or “other,” skip to **Question c** to obtain the year of the event.
- b. Record the number of babies that were born for that pregnancy (for live births and stillbirths).
- c. Record the month and year of each pregnancy outcome. If the participant cannot remember the month and/or the year after probing, record “<-8>” in the appropriate field. **DO NOT LEAVE BLANK.**

NOTE: The number of pregnancies recorded in Question D3 should be consistent with the number of pregnancy outcomes in Questions D4 through D10.

After recording the participant's last pregnancy outcome, skip to **Question D11**.

- D11. Indicate if the participant has ever breastfed. If response is “NO,” skip to **Question D12**.
- a. If the participant reports having breastfed, record the total number of months in her lifetime that she has breastfed. If the participant reports the number of total years she has breastfed, the interviewer should convert to months.

PROMPT: IF PARTICIPANT IS CURRENTLY PREGNANT, SKIP TO QUESTION D14.

- D12. Has the participant ever had a hysterectomy (**PROBE: removal of the uterus or womb**)? If the participant answers “NO,” skip to **Question D14**.
- a. We would like to know the year the participant had her hysterectomy. **PROBE: Please try to remember as best you can.** Record as “<-8>” if participant cannot remember, after probing.

D13a-f. We would like to determine the reason that the participant had a hysterectomy. Please code each item (a-f), as “YES” or “NO” because it is possible that the participant could have had more than one of these complications/conditions.

PROMPT: IF D13c = YES, THEN COMPLETE ABSTRACT CHECKLIST AND OBTAIN MEDICAL RECORD RELEASE.

- D14. We would like to know whether the participant has had one ovary or both ovaries removed.
- D15. Has the participant ever had a permanent sterilization procedure, such as having a tubal ligation (tubes tied) or Essure procedure? If participant answers “NO,” skip to **Question D16**.
- a. We are interested in knowing if the participant had her permanent sterilization procedure reversed. This is defined as *“surgery to open a woman's tubes so she can become pregnant again.”*
- D16. We would like to know if the participant has ever taken the Pill or oral contraceptives. If participant answers “NO,” skip to **Question D17**.
- a. We would like to know for approximately how many years altogether the participant has used the Pill. The total number of years should be considered. If the participant's use was intermittent, she should consider all the times she used it and add them up; the key word is “altogether.”
- D17. We would like to know whether the participant has ever had a Pap smear. **PROBE:** *Papanicolaou test, a test for early detection of cancer of the cervix.* If she responds “NO,” skip to **Question D19**.
- a. We would like to know when the participant had her last Pap smear. Record only the year of her last Pap test. **PROBE:** *Please estimate as best you can.*
- D18. We would like to know if the participant has ever been told she had an abnormal Pap test by a health care provider, that is, a doctor, nurse, nurse practitioner, midwife or physician's assistant.
- D19. We would like to know if the participant has ever had a colposcopy. **PROBE:** *Colposcopy uses an instrument like binoculars to examine the cervix, and a biopsy may or may not have been taken.*
- D20. Indicate whether the participant has ever been treated for any cervical abnormality. If response is “NO,” skip to **Question D22**.
- D21. Indicate the type of treatment received by the participant for her cervical abnormality.
- D22. Indicate whether the participant has ever been treated for any other gynecological conditions. If response is “NO,” skip to **Question D23**.
- a. Record the gynecological condition for which the participant received treatment.
- D23-31. We want to know if the participant has ever been told by a doctor, nurse, nurse practitioner, midwife or physician's assistant that she had any of the conditions listed here.
- D27. We would like to know if the participant has ever been told she had herpes in or around her genital area. **PROBE:** *your vagina or anus.* Do not explain further. However, if the participant responds with terms such as: “tush,” “behind,” “vulva,” “labia,” “crotch,” or “butt,” code “1” (YES).
- D28. We would like to know if the participant has ever been told she had warts in or around her genital area. **PROBE:** *your vagina or anus.* Do not explain further. However, if the participant responds with terms such as: “tush,” “behind,” “vulva,” “labia,” “crotch,” or “butt,” code “1” (YES).
- D32. We would like to know if the participant has ever had a mammogram. **PROBE:** *A mammogram is a special type of x-ray for examining the breast.* If the participant answers “NO,” skip to **Section E**.

- a. We would like to know the year of the participant's most recent mammogram. **PROBE:** *Please remember as best you can.* Record the year reported by the participant in the space provided.

D33. We would like to know the reason for the participant's most recent mammogram. If the participant answers "For another reason," please ask her to specify. Record participant's answer verbatim.

SECTION E. ALCOHOL, DRUG USE AND SEXUAL BEHAVIOR

E1. We want to learn about the participant's smoking history as it relates to her general health status and HIV progression. This question serves as a qualifier to avoid asking questions regarding the smoking patterns and behavior of a participant who only experimented with cigarettes. If the participant has not smoked at least 100 cigarettes (**PROBE: about five packs**) in her lifetime, skip to **Question E6**.

E2. We would like to know if the participant currently smokes. If the participant responds "YES," circle "1" and skip to **Question E5** to obtain information about her current smoking habits. If the response is "NO," continue with **Question E3** to obtain information about the participant's smoking habits before she quit.

E3. Record the month and the year when the participant quit smoking cigarettes. If she responds that she has quit several times, probe for the most recent time she quit. If she has difficulty remembering the exact date, use non-directive probes that will help her focus on a time line. The example below illustrates a proper probing sequence:

Participant: I don't remember the last time I quit.

Interviewer: Do you remember about how old you were when you quit?

Participant: I was about 25 when I quit.

Interviewer: What year was that?

Participant: I was 25 two years ago. I guess that would be in 1992.

Interviewer: Do you remember the month that you quit?

Participant: No, not really.

Interviewer: Do you remember what season it was?

Participant: Oh yea. It was warm outside – it was Memorial Day – in May.

E4. Record the number of cigarettes or packs of cigarettes that the participant smoked on average before quitting.

E5. For this question, read the phrase "**have you smoked,**" if the participant currently smokes, OR "**did you smoke**" if she has quit smoking. There are two fields for recording the number of years and the number of months. You must fill in both of these fields, so, if the participant gives a response in only one unit, for example, "two years," write "02" in the "YEARS" field and "00" in the "MONTHS" field. Similarly if the response is given in months, write in the number of months and "00" in the "YEARS" field. If a fractional answer is given, such as, "Two and a half years," code as:

0 2	0 6
YEARS	AND MONTHS

to indicate two years and six months. If the participant says that she has started and stopped smoking several times, the interviewer must use non-directive probes that do not calculate the time for the participant. So if a participant says that she "smoked for two years then quit for one then smoked for another year," a directive and incorrect probe would be: "So you smoked for three years altogether?" The proper probe is to repeat the question stressing the word "*altogether*" and then read the probe provided in parentheses.

- E6. This next set of questions is used to obtain information related to past changes in drinking behaviors. More specifically, these next few questions focus on whether the participant has ever drunk more than she has in the past six months. This question is a qualifier for this series. If the response is “NO” skip to **Question E10**.
- a. Ask participant to refer to **Response Card 9NR**. The purpose of this question is to ascertain *how often* during an average week the participant had a drink containing alcohol during the period when she drank more. Read the question and, if necessary, read each response choice. Use probes that encourage her to choose one category if she has difficulty responding. **PROBE: Which choice is closest?**
 - b. Record the average number of drinks the participant had on the days she drank during that time. If the participant cannot give an exact answer, obtain a range by using a probe such as, **“Can you give me a range of about how many drinks?”** Record the lowest number of the range given in the spaces provided. If the participant is not able to average after probing or if her response cannot be easily converted into number of drinks (e.g., “a ½ pint of vodka”), record the response verbatim in the SPECIFY space provided. Responses will be data entered verbatim.
- E7. Record the age at which the participant began drinking at the higher level specified in **Questions E6a** and **E6b**.
- E8. Record the age at which the participant cut back or stopped drinking at the higher level specified in **Questions E6a** and **E6b**.
- E9. **Subtract** the age recorded in **Question E7** from that recorded in **Question E8** and insert it into the blank in **Question E9**. Ask the participant if this sounds like the correct number of years during which she drank at this higher level. If not, start again at **Question E7** and try to determine the correct number of years.
- E10. This question serves as a qualifier to skip out participants who have never been in an alcohol treatment program. Examples of treatment programs are listed in the question. If the participant requires further clarification, the interviewer might repeat the phrase, **“I am interested in any treatment programs you may have been in...”** stressing the word “any.” If the participant answers, “NO” to this question, skip to **Question E11**.
- a-e. If the participant indicates that she has been in an alcohol treatment program (“YES” at **Question E10**), read the question stem above **Questions a** through **b**, which asks, **“What programs?”** For each program mentioned, circle “1” for “MENTIONED” and ask Question “i,” **“Have you been in [PROGRAM] during the past six months?”** Insert the name of the program mentioned where [PROGRAM] appears. Probe for other programs by asking, **“Any others?”** When the participant is done naming the programs, circle “2” for “NOT MENTIONED” next to each of the programs she did not mention.
- E11. Indicate whether the participant has ever used marijuana (either medically or recreationally), cocaine, crack, heroin, amphetamines or methamphetamine, hallucinogens, club drugs, methadone or narcotics when they were not prescribed by a doctor, or any other illicit or recreational drugs. If response is “NO,” skip to **Question E30**.
- E12-E27. The purpose of these questions is to collect lifetime history 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 ever 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.
- a. This question inquires as to the participant’s average use of the substance listed in that particular question. 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 question 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.

- E23. This 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.
- E28. Indicate whether the participant has ever had a nosebleed while sniffing or snorting drugs.
- E29. Indicate whether anyone else has ever had a nosebleed while the participant was sniffing or snorting drugs with them.
- E30. Indicate whether the participant has used any tranquilizers, such as sleeping pills, barbiturates or valium, whether or not they were prescribed by a doctor.
- E31. Based on the participant's responses to **Questions E14** (injected crack), **E16** (injected cocaine), **E19** (injected heroin), **E20** (injected speedball), **E22** (injected methamphetamine), and **E27b** (injected narcotic drugs), indicate whether or not she has ever injected any drugs. If "NO," skip to **Question E40**.
- E32. Indicate the participant's age when she first injected street drugs.
- E33. Indicate the participant's age when she last injected street drugs.
- E34. Indicate the frequency with which the participant injected street drugs, when she used them.
- E35. Indicate if the participant has ever, even once, used a needle or works after someone else had used it. 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. 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.
- E36. Indicate the participant's age when she first used a needle or works after someone else had used it.
- E37. Indicate the participant's age when she last used a needle or works after someone else had used it.
- E38. Indicate how often the participant used a needle or works after someone else had used it.
- E39. 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."*
- E40. This question serves as a qualifier to skip out participants who have not been in a drug treatment program. Examples of treatment programs are listed as part of the question. If the participant requires further clarification, the interviewer can repeat the phrase, *"I am interested in any drug treatment programs you may have been in."* If the participant answers "NO," skip to **Question E41**.
- a-g. If the participant indicated (in response to **Question E40**) that she has been in a drug treatment program, read the stem question above **Questions a** through **g** (i.e., *"What programs?"*) and wait for the participant's response. For each treatment program she mentions, circle code "1" (for YES) and proceed to Question "i," which asks how many different times she has started that particular program. When reading Question "i," insert the name of the program she mentioned where [PROGRAM] appears. After obtaining a response, if indicated, proceed to Question "ii" to find out how many days (total) she has been in that program. Continue to probe for other programs by asking, *"Any others?"* Once the participant responds "NO" to your probe for any other programs, circle code "2" (for NO) for all of the programs she did not mention.

- i. Since this question inquires about the number of different occasions that the participant checked herself into or began a drug treatment program, it will capture information pertaining to participants who enroll, drop out, and re-enroll into various programs. This question is asked of all the listed treatment programs except “Narcotics Anonymous.”
- ii. We would like to know the total number of days the participant has been in each type of treatment. If she has started and stopped several times, she should add up all the days she was in that particular type of treatment and give a total number. If the participant cannot give an exact answer, probe for a range (e.g., “*Can you give me a range of about how many days?*”). Record the lowest number from the range in the space provided. If the participant can provide the number weeks or months she spent in a particular treatment program, the interviewer should calculate the number days based on the participant’s response. Interviewers should have a calendar available to aid the participant in determining how many days she spent in treatment. Question “ii” is asked of all types of treatment programs listed in **Questions a through g**.

E41-E49. **Questions E41 through E49** refer to sexual practices with all male partners throughout the participant’s entire life. The words “men or boys” have been included in parentheses to use for clarification if needed. This has been added to ensure that the participant includes all of the males she has had sex with regardless of both of their ages at the time.

E41. We want to know how many different males (altogether) the participant has had sex with throughout her entire lifetime. The words “men or boys” have been included in parentheses to use for clarification if needed. This has been added to ensure that the participant includes all of the males she has had sex with regardless of both of their ages at the time. The word “partner” has purposely not been used to ensure that the participant includes all males with whom she has had a sexual encounter of any kind, with or without consent.

The probe should be used if the participant indicates confusion or difficulty in answering this question. Here, “sex” includes vaginal, both types of oral, and anal sex. Optional descriptions of sexual practices have been provided in parentheses to use as needed.

Record the number using leading zeros. For example: “3” should be recorded as “003.” If the participant refuses 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 states that she “doesn’t know,” ask: “*Could you tell me what your best estimate might be?*” This question may require non-directive probing to ascertain the total. If, after probing non-directively, the participant still cannot give an exact number, obtain a range by using a probe such as, “*Can you estimate by giving me a range?*” Record the lowest number of the range given. For example: If the participant says, “I don’t know... more than 100,” record “100” in the field. Similarly if the participant says, “between 50 and 75,” record “050” in the field.

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. Read the prompt and follow with **Question E42** if the participant has had sex with a male.

If the participant reports more than 999 partners, record “999” in the field and write the actual number next to the field. If the participant answers “NONE” to this question, record “000” and skip to **Question E49**.

E42. We want to know the participant’s age when she had her first sexual encounter with a man or boy with or without consent. This information is important for the scientific research question relating to cervical cancer (associated with early sexual activity with a male). If the participant indicates confusion or difficulty in answering the question, or asks what we mean by “sexual encounter,” repeat the definitions of “sex” from **Question E41** (i.e., vaginal sex, both types of oral sex, or anal sex).

If the participant has difficulty providing her exact age, ask her: ***“What would be your best guess of your age at the time?”*** Record the participant's age to the nearest whole number. Rounding up or down to the nearest year should follow the following principle: If less than six months, record the lower number; if greater than or equal to six months, record the higher number. For example 14-1/2 should be recorded as “15;” but 14 and 3 months should be recorded as “14.” If the participant cannot provide an exact age, obtain a range by using a probe such as, ***“Can you give me a range of about how old you were?”*** Record the youngest age of the range given.

If, after probing, the participant still cannot give any response at all, code the response as **“DON'T KNOW”** by recording “<-8>” in the field and writing **“DON'T KNOW”** or **“DK”** beside the field to confirm the missing data. Similarly, if the participant refuses to answer the question after assurances about confidentiality have been reiterated, code the response as **“DECLINED”** by recording “<-7>” in the field and writing **“DECLINED”** or **“DECL”** adjacent to the field to confirm the missing data. Then go on to the next question.

Be prepared for participants who may indicate psychological distress when asked this question, since the first sexual encounter may have been when she was still a child and/or it may have occurred without her consent.

NOTE: IF THE RESPONDENT INDICATES EMOTIONAL DISTRESS, STOP THE INTERVIEW AND ASK IF SHE NEEDS TO TAKE SOME TIME BEFORE CONTINUING THE INTERVIEW. THE RESPONDENT SHOULD DECIDE WHEN SHE IS READY TO CONTINUE THE INTERVIEW. IN THIS CASE, THE INTERVIEWER SHOULD BE READY TO PROVIDE A REFERRAL FOR PSYCHOLOGICAL COUNSELING AT THE END OF THE INTERVIEW.

E43-E46. These questions are designed to collect data regarding the participant's past sexual risk behavior with male partners. All of these questions are phrased **“to your knowledge.”** First, read the stem at the top (left) of page, followed by the phrase at **Question E43**. Repeat the stem, followed by the phrases at **Questions E44, E45, and E46**.

E47. We want to know how many different males (altogether) the participant has had sex with in the past five years. This question is asked to obtain an important piece of information for use in assessing the participant's past sexual risk behavior. The words “including men or boys” are shown in parentheses to use for clarification if needed. This has been added to ensure that the participant includes all of the males she has had sex with in the past five years regardless of both of their ages at the time. The same rules apply as outlined above for **Question E41** regarding ranges and responses of “DON'T KNOW” and “DECLINED.” This includes any sexual encounter with a man or boy; and with or without the participant's consent.

E48. This question asks if the participant has ever had anal sex with a male partner. This includes anal sex with a man or boy; and anal sex with or without the participant's consent. Again, words for clarification of the term “anal sex” are provided in parentheses and should be used if the participant indicates difficulty or confusion in answering the question.

E49. The next series of questions refer to sex with female partners. We want to know if the participant has ever had sex with any female sexual partners. The words “woman or girl” have been included in parentheses to use for clarification if needed. This has been added to ensure that the participant includes females she has had sex with regardless of their ages at the time. The word **“partner”** has purposely not been used to ensure that the participant includes female sexual encounters of any kind, with or without consent. Here, “sex” includes vaginal, oral, and anal sex. Optional descriptions of sexual practices have been provided in parentheses to use as needed for clarification.

If the participant answers “NO” or if she declines to answer, skip to **Question E55**.

E50. We want to know how many different females (altogether) the participant has had sex with throughout her entire lifetime. The words “women or girls” have been included in parentheses to use for clarification if needed. This has been added to ensure that the participant includes all of the

females she has had sex with regardless of their ages at the time. The word “partner” has purposely not been used to ensure that the participant includes all females with whom she has had a sexual encounter of any kind, with or without consent. Record the number using leading zeros. For example: “3” should be recorded as “003.”

If the participant refuses to give a number, code the response as “DECLINED” by writing “<-7>” in the field and writing “DECLINED” or “DECL” beside the field to confirm the missing data.

If the participant states that she “doesn't know,” ask: “*Could you tell me what your best estimate might be?*” This question may require non-directive probing to ascertain the total. If, after probing non-directively, the participant still cannot give an exact number, obtain a range by using a probe such as, “*Can you give me a range of about how many?*” Record the lowest number of the range given. For example: If the participant says, “I don't know, more than 100,” the interviewer would record “100” in the field. Similarly, if the participant said, “Between 50 and 75,” the interviewer would record “050.” If, after probing, the participant still cannot give **any** response at all, code the answer as “DON'T KNOW” by writing “<-8>” in the field and recording “DON'T KNOW” or “DK” beside the field to confirm the missing data.

If the participant reports having had sex with more than 999 females, record “999” in the field and write the actual number next to the field.

E51-E52. These two questions are designed to collect data regarding the participant's past sexual risk behavior with female partners. Both of these questions are phrased “to your knowledge.” First, read the stem at the top (left) of page, followed by the phrase at **Question E51**. Repeat the stem, followed by the phrase at **Question E52**.

E53. We want to know how many different females (altogether) the participant has had sex with in the past five years. This question is asked to obtain an important piece of information for use in assessing the participant's past sexual risk behavior. The words “including women or girls” are shown in parentheses to use for clarification if needed. This has been added to ensure that the participant includes all of the females she has had sex with in the past five years regardless of both of their ages at the time. This includes any sexual encounter with a woman or girl; and with or without the participant's consent. Record the number using leading zeros. For example: “3” should be recorded as “003.”

If the participant refuses to give a number, code the response as “DECLINED” by writing “<-7>” in the field and writing “DECLINED” or “DECL” beside the field to confirm the missing data.

If the participant states that she “doesn't know,” ask: “*Could you tell me what your best estimate might be?*” This question may require non-directive probing to ascertain the total. If, after probing non-directively, the participant still cannot give an exact number, obtain a range by using a probe such as, “*Can you give me a range of about how many?*” Record the lowest number of the range given. For example: If the participant says, “I don't know, more than 100,” the interviewer would record “100” in the field. Similarly, if the participant said, “Between 50 and 75,” the interviewer would record “050.” If, after probing, the participant still cannot give any response at all, code the answer as “DON'T KNOW” by writing “<-8>” in the field and recording “DON'T KNOW” or “DK” beside the field to confirm the missing data.

E54. This question asks if the participant has ever had anal sex with a female partner. This includes anal sex with a woman or girl; and anal sex with or without the participant's consent. Again, words for clarification of the term “anal sex” are provided in parentheses and should be used if the participant indicates difficulty or confusion in answering the question

E55. We want to know how the participant describes her sexual orientation. Read all of the response categories listed and circle the appropriate number. **ACCEPT ANY ANSWER GIVEN BY THE RESPONDENT WITHOUT COMMENTING ON HER BEHAVIOR OR SEXUAL ORIENTATION. DO NOT ATTEMPT TO RECONCILE THIS RESPONSE WITH ANY PREVIOUS ONES REGARDING HER SEXUAL BEHAVIORS.** If the participant gives an answer

that is different from the three categories listed, circle “4” for “Other” and write her response verbatim on the specify line.

- E56. We would like to know whether the participant has ever received drugs, money or shelter from anyone (male or female) in exchange for having any type of sex. If the participant answers “YES” to **Question E56**, proceed to **Question a**. If she answers “NO”, then skip to **Question E57**.
- a. Indicate if the participant has ever received drugs in exchange for having any type of sex.