

WOMEN'S INTERAGENCY HIV STUDY
QUESTION BY QUESTION SPECIFICATIONS
FORM 22HX: FOLLOW-UP HEALTH HISTORY

General Instructions:

NOTE: If this form is being administered to the participant AFTER her WIHS physical exam, be sure to remind her that the findings from her exam conducted today do NOT apply to the questions you are about to ask her.

1. 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 (and 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.

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

READ THE INTRODUCTION TO THE PARTICIPANT.

SECTION B: SYMPTOMS

- B1–B11: We want to know if the participant has experienced non-specific symptoms associated with HIV infection or medication use since her (MONTH) study visit.
- B1. Indicate if the participant experienced a fever for more than one month straight. If the symptom did not last more than one month, circle "2" (NO). **PROBE: "Did you have a fever for more than one month?"**
- B3–B4: Indicate if the participant experienced these symptoms for more than two weeks. If the symptom did not last more than two weeks, circle "2" (NO). **PROBE: "Did you have (CONDITION) for more than two weeks?"**
- B5. Indicate if the participant had an unintended weight loss of 10 pounds or more that lasted for more than a month, since her (MONTH) study visit. Dieting and/or fasting are methods of intended weight loss and are not considered "unexpected," – circle "2" (NO). If the participant specifies an unintentional weight loss of 10 pounds or more because of HIV infection or AIDS, circle "1" (YES).
- B6. Indicate if the participant has experienced any confusion, such as getting lost in a familiar place or the inability to perform routine mental tasks, since her (MONTH) study visit.
- B7. Indicate if the participant has experienced drenching night sweats since her (MONTH) study visit.

- B8. Indicate if the participant has experienced nausea and/or vomiting since her (MONTH) study visit.
- B9. Indicate if the participant has experienced dry mouth since her (MONTH) study visit.
- B10. Indicate if the participant has experienced diarrhea since her (MONTH) study visit.
- B11. Indicate if the participant has experienced constipation since her (MONTH) study visit.

REMEMBER TO REFER THE PARTICIPANT (AT THE END OF THE INTERVIEW) FOR ANY "YES" RESPONSES (AS INDICATED BY SHADED BOXES).

READ THE INTRODUCTION TO THE PARTICIPANT. THE QUESTIONS IN B12 ASK ABOUT CHANGES A PARTICIPANT MAY HAVE NOTICED IN THE SHAPE OF HER BODY. THEY REFER TO THE PERIOD OF TIME BETWEEN NOW AND HER LAST STUDY VISIT. DO NOT INCLUDE ANY CHANGES THAT ARE DUE TO PREGNANCY. USE BODY DIAGRAM CARD AS NEEDED.

- B12. Ask the participant if she has experienced any changes in the shape of her body or in the amount of her body fat. Use the body diagram card to point out the location of the supraclavicular and dorsocervical fat pads and, as needed, to clarify any other body area. If the participant answers “NO,” skip to **Question B13**. If she answers “YES,” read **Questions B12a** through **B12j** to the participant.
- a–j: If the participant reports a change in any specific body area, continue by asking if the change was an increase or a decrease in size.
- B13. These questions are intended to qualify the body measures recorded during the physical exam (*Form 07*). Indicate if the participant has taken any of the actions to change or maintain the shape of her body listed in **Questions B13a** through **B13d**.
- c. This question is intended to capture information concerning cosmetic surgeries that may affect the body measures recorded during the physical exam, including implants or injections. We are only trying to capture cosmetic surgeries that may influence these body measures.
- d. This question is intended to capture information concerning weight-loss surgeries, such as gastric bypass surgery or gastric stapling.

SECTION C: MEDICAL CONDITIONS AND CONCOMITANT ILLNESSES/SYMPTOMS

THE QUESTIONS ASKED IN SECTIONS C AND D ARE ASKED OF BOTH SEROPOSITIVE AND SERONEGATIVE WOMEN. MANY OF THESE QUESTIONS REFER TO “HIV INFECTION/AIDS” RELATED CONDITIONS. SOME WOMEN MAY BECOME WORRIED OR UPSET WHILE BEING ADMINISTERED THESE SECTIONS. 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.

IN QUESTIONS C1 THROUGH C15, IF THE PARTICIPANT SELF REPORTS A DIAGNOSIS OF CANCER, BUT LATER REPORTS THAT SHE HAD NO BIOPSY, THE INTERVIEWER SHOULD ASK FOR CLARIFICATION FROM THE PARTICIPANT. FOR EXAMPLE, AFTER THE PARTICIPANT INDICATES THAT SHE HAS NOT HAD A BIOPSY, THE INTERVIEWER COULD SAY, “Did your doctor tell you that you definitely had cancer, or just that s/he suspected you might have cancer and should return for more tests?” SINCE CANCER CAN’T BE DIAGNOSED WITHOUT A BIOPSY, IF THE PARTICIPANT REPORTS THAT SHE HAD NO BIOPSY, THE INTERVIEWER SHOULD ENSURE THAT THE FORM DOES NOT INDICATE A CANCER DIAGNOSIS.

- C1. a. Indicate if the participant remembers being told by a health care provider (doctor, nurse, physician's assistant or nurse practitioner) since her (MONTH) study visit that she had cervical cancer. Skip to **Question C2** if the participant answers "NO."
- b. Record whether the participant has had surgery to treat cervical cancer since her (MONTH) study visit. **PROBE: "Been admitted to the hospital and had surgery in an operating room."**
- c. Record whether the participant has had a CAT or MRI scan of her abdomen since her (MONTH) study visit. **PROBE: "A big donut-shaped machine that takes special pictures."**
- d. Record whether the participant has been told that she needs either surgery or radiation therapy since her (MONTH) study visit.
- C2. Indicate if the participant remembers being told by a health care provider since her (MONTH) study visit that she had any other type of cancer besides cervical cancer. This includes any other kind of cancer (such as skin cancer, breast cancer, ovarian cancer, etc.). Skip to **Question C13** if the participant answers "NO."
- C3. Ask the participant if she was told she has breast cancer since her (MONTH) study visit. If she answers "NO," skip to **Question C4**. If "YES," ask **Question C3a**.
- a. Ask the participant if she has had a lump removed from her breast by a surgeon. **PROBE: "Not a needle biopsy, but an incision resulting in stitches."**
- b. Ask the participant if she has had a mastectomy. **PROBE: "Removal of entire breast."**
- C4–C12: Ask the participant whether or not she has been told she has each kind of cancer as listed in **Questions C4** through **C12**.
- C13. The interviewer should record the total number of cancers self-reported by the participant at this visit. 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 THROUGH 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 – 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 6.

- 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**. They are asked to determine whether or not she 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 **subquestion a**.

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

- b. If this is the participant's first diagnosis of cancer, proceed to **subquestion c**; if not, skip to **subquestion e**.

- c. If the participant was told that this cancer had metastasized to another part of her body, proceed to **subquestion 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 the location to which 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 **subquestion 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 C1 THROUGH C12 = YES, THEN COMPLETE ASCERTAINMENT TRACKING CHECKLIST (ATC) FOR EACH ILLNESS AND OBTAIN MEDICAL RECORD RELEASE. ALSO, IF EITHER C14c/C15c OR C14e/C15e = YES, THEN COMPLETE ATC FOR METASTATIC CANCER.

- C16. Indicate if the participant has received cancer chemotherapies since her (MONTH) study visit. Do not explain further.
- C17. Indicate if the participant has received radiation treatments since her (MONTH) study visit. Do not explain further.
- C18. Indicate if the participant has been told she has asthma since her (MONTH) study visit. If the participant already has asthma, we want to know whether her asthma has worsened since her (MONTH) study visit. For WIHS purposes, reports of this condition DO NOT require diagnosis by a health care provider (doctor, nurse, nurse practitioner or physician's assistant).
- C19–C21: These questions are about tuberculosis. Tell the participant we are referring to tuberculosis as “TB” for short.
- C19. Indicate if anyone in the participant's family or anyone she has lived with has had TB since her (MONTH) study visit. DO NOT DEFINE “tuberculosis,” “family” or “lived with.”
- C20. Indicate if the participant has had TB since her (MONTH) study visit. For WIHS purposes, reports of this condition DO NOT require diagnosis by a health care provider. Skip to **Question C22** if participant answers “NO.”
 - a–b: Indicate where in her body the participant had TB. These questions ask about the location of TB, whether it was in her lungs or another part of her body. If the participant answers “other,” record her answer verbatim in the space provided. The definition of these conditions is up to the participant. DO NOT explain further.
 - c. Indicate if the participant received a chest x-ray for tuberculosis since her (MONTH) study visit.
 - d. If the participant remembers being treated for TB, we want to know if she took medications for three months or longer.

PROMPT: IF ANY OF C20 or C20a–d = YES, THEN COMPLETE THE ASCERTAINMENT TRACKING CHECKLIST FOR EACH ILLNESS AND OBTAIN MEDICAL RECORD RELEASE.

- C21. Indicate if the participant has had a skin or a blood test for TB since her (MONTH) study visit. Skip to **Question C31**, if participant answers “NO,” “DON'T KNOW” or declines to answer this question.

- a. Indicate the last time (most recent time) the participant had a skin or a blood test for TB. Interviewers should have a calendar available to aid the participant in determining the date of her last skin or blood test. **PROBE: “I need the month and the year. Please estimate as best you can.”**
- b. Indicate if the participant remembers being specifically told that her TB test was positive (that her skin or blood test showed exposure to TB).

PROMPT: IF C21b = YES, THEN COMPLETE THE ASCERTAINMENT TRACKING CHECKLIST AND OBTAIN MEDICAL RECORD RELEASE.

- C31a–g: 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 that require medical care. In evaluating the progression of HIV in women, it is important to take into consideration the effect other illnesses may have in relation to HIV disease. These questions ask about conditions that **REQUIRED OR REQUIRE** medical care. **We want to know if the participant has had any of these conditions since her (MONTH) study visit.** If the participant does not recognize the medical terminology, circle “2” (NO). **DO NOT LEAVE ANY QUESTIONS BLANK.**
- a. Indicate if the participant remembers having a sinus infection that required treatment with antibiotics.
 - c. Indicate if the participant remembers having high blood pressure or hypertension (blood pressure that is above the normal range) since her (MONTH) study visit.
 - d. Indicate if the participant remembers having high blood sugar or diabetes. **Do not define further.**
 - e. Indicate if the participant remembers having high blood cholesterol, high triglyceride or blood lipid levels.
 - f. Indicate if the participant remembers having any rheumatologic disease including rheumatoid arthritis or lupus.
 - g. Indicate if the participant remembers having depression that required medical care.
- C32. a. Indicate whether the participant has been told by a health care provider since her (MONTH) study visit that she had low bone mineral density (**PROBE: “a measurement of the level of minerals in the bones, which indicates how dense and strong they are”**) or osteopenia (**PROBE: “lower than normal bone mineral density”**) or osteoporosis (**PROBE: “a progressive disease that causes bones to become thin and brittle, making them more likely to break”**).
- C33. This series of questions asks about fractures to the hip, wrist, spine, and any other bones, that the participant may have had since her (MONTH) study visit. If a participant answers “YES” to a hip fracture then ask **Question C33a2** (how did the fracture occur). Do the same for wrist (**C33b**), spine (**C33c**) and other bone (**C33d**) fractures. **NOTE: If the participant reports that she fractured her tailbone, this should not be recorded in Question C33c as a spinal fracture, but should be recorded in Question C33d as a fracture of another bone.** If the response to **Question C33d** is “YES,” specify the location of the bone that was fractured in **Question C33d1**.
- Options for how the fracture occurred include: (1) as a result of a fall from standing height or less (includes falls due to slipping or tripping); (2) because of a harder fall, such as falling down steps; (3) from a car accident or other severe external force.
- C34. These questions ask about different liver conditions the participant may have had since her (MONTH) study visit. If she reports having no liver disease diagnoses since her last visit, skip to **Question C35**.

- a. Ask if the participant has been diagnosed since her (MONTH) study visit with “fatty liver,” a build-up of fat in the liver cells.
 - b. Ask if the participant has been diagnosed since her (MONTH) study visit with alcoholic liver disease.
 - c. Ask if the participant has been diagnosed since her (MONTH) study visit with cirrhosis. If she has not been diagnosed with cirrhosis, skip to **Question C34d**.
 - i. Ask if the participant has been diagnosed since her (MONTH) study visit with abnormal fluid in the belly (ascites).
 - ii. Ask if the participant has had bleeding from enlarged veins in her esophagus or stomach (varices) since her (MONTH) study visit.
 - iii. Ask if the participant has been diagnosed since her (MONTH) study visit with hepatic encephalopathy (confusion or decreased awareness caused by liver disease).
 - d. Indicate if the participant has been tested for liver cancer since her (MONTH) study visit. If she has not been tested for liver cancer, skip to **Question C35**.
 - i. Ask if the participant had a blood test to look for liver cancer (called AFP or alpha-fetoprotein).
 - ii. Ask if the participant had an ultrasound or CT (CAT) scan to look for liver cancer.
- C35. Indicate if the participant remembers having received a new diagnosis of hepatitis C since her (MONTH) study visit. Only record “YES” if it was a new diagnosis. If “NO,” skip to **Question C38**.
- C36c. Indicate if anyone has offered the participant treatment for hepatitis C since her (MONTH) study visit.
- C38. Indicate whether or not the participant had a liver biopsy for any reason. If the participant answers “NO,” skip to **Question C39**. If the participant answers “YES,” indicate the reason for the biopsy in **Question C38a**.
- a. If the participant reports having had a liver biopsy (**Question C38** is “YES”), ask the participant to indicate the reason why. If the participant answers “other,” record her answer verbatim in the space provided.

PROMPT: IF C38 = YES, THEN COMPLETE AN ASCERTAINMENT TRACKING CHECKLIST AND OBTAIN MEDICAL RECORD RELEASE.

- C39. Ask if the participant has been told by a health care provider that she needed a liver transplant since her last visit. If “NO,” skip to **Question C42**.
- C40. Ask if the participant has had a liver transplant since her last visit.
- C41. Ask if the participant is currently on a waiting list for a liver transplant.
- C42a–d: These questions ask about different cardio- or cerebro-vascular conditions the participant may have had diagnosed since her (MONTH) study visit. If the participant does not recognize the medical terminology, circle “2” (NO). **DO NOT LEAVE ANY QUESTIONS BLANK.**
- a. Indicate whether or not the participant has received a new diagnosis of angina or chest pain related to heart disease. **NOTE: No ATC record will be generated for a “YES” answer to Question C42a.**
 - i. Ask if the participant was hospitalized due to angina or chest pain related to heart disease. **NOTE: A “YES” answer to Question C42ai will generate an ATC record for disease code 334.**

- b. Indicate whether or not the participant has received a new diagnosis of congestive heart failure or CHF. **NOTE: No ATC record will be generated for a “YES” answer to Question C42b.**
 - i. Ask if the participant was hospitalized due to congestive heart failure or CHF. **NOTE: A “YES” answer to Question C42bi will generate an ATC record for disease code 332.**
- c. Indicate whether or not the participant has had a heart attack (myocardial infarction or MI). **NOTE: A “YES” answer to Question C42c will generate an ATC record for disease code 331.**
- d. Indicate whether or not the participant has had a stroke (CVA). **NOTE: A “YES” answer to Question C42d will generate an ATC record for disease code 333.**
- e. Indicate whether or not the participant has had a transient ischemic attack (TIA) or mini-stroke. **NOTE: A “YES” answer to Question C42e will generate an ATC record for disease code 335.**

C44. Ask if the participant has ever had any surgery or procedure to look for or to open blocked vessels. (**PROBE: “Your doctor may have called this: cardiac catheterization, percutaneous revascularization, PTCA, angioplasty, stenting, carotid endarterectomy, surgical revascularization, CABG, or coronary artery bypass grafting.”**) If the participant says “yes,” proceed to **Questions C44a and C44b.**

C44a-b. Record if the procedure or surgery mentioned in **Question C44** was on heart vessels (a) or other vessels (b). If the participant responds “yes” to either question, proceed to **subquestion i** to indicate what procedure was performed. **NOTE: A “YES” answer to Question C44a will generate an ATC record for disease code 337. No ATC record will be generated for a “YES” answer to Question C44b.**

C45. Indicate whether the participant takes aspirin three days or more of every week.

PROMPT: IF ANY OF C42ai, C42bi, C42c, C42d, C42e OR C44a = YES, THEN COMPLETE ASCERTAINMENT TRACKING CHECKLIST.

C46. Ask if the participant has had a serious head injury since her last study visit. (**PROBE: “A serious head injury may also 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 C48.**

- a. Ask how many head injuries the participant has had since her last visit.

PROMPT: FOR EACH HEAD INJURY INDICATED IN QUESTION C46a, COMPLETE QUESTIONS C47a-g. THE NUMBER OF SUBFORMS COMPLETED MUST EQUAL THE VALUE RECORDED AT C46a. IF THE TOTAL NUMBER OF REPORTED HEAD INJURIES IS GREATER THAN ONE, PLEASE XEROX THIS PAGE AND INSERT THE COPY AFTER PAGE 13.

- C47.
 - a. Record how the head injury happened. If the participant had some kind of fall, slip, or trip and hit her head on the ground or on an object such as a rock or table, circle “1.” If the injury resulted from a car accident, circle “2.” If the injury occurred as a result of an accident while playing sports, circle “3.” If the injury resulted from physical violence, for example, another person hitting the participant in the head, or a gun shot, then circle “4.” If the participant cannot place the cause of the injury into any of these categories, circle “5” and complete the specify field.
 - b. Ask how old the participant was, in years, at the time of the injury.
 - c. Ask if the participant visited a doctor because of the injury.
 - d. Ask if the participant stayed overnight in a hospital because of the injury.
 - e. Ask if the participant lost consciousness because of the injury. If the participant did not lose consciousness, then skip to **Question C47f.**

- i. If the response to **Question C47e** is “YES,” ask how long the participant lost consciousness. (**PROBE:** “*How many minutes?*”) Record the number and indicate if this was in minutes, hours, or days.
 - f. Ask if the head injury caused a skull fracture. A skull fracture is an event in which one or more of the bones that make up the skull are broken. Some skull fractures are visible. Blood and bone fragments may be obvious. In some cases, however, there are no visible signs of a skull fracture.
 - g. Ask if the participant had a seizure or fit within seven days after the head injury.
- C48. Ask the participant if she is currently on dialysis.

SECTION D: SKIN AND ORAL CONDITIONS

NOTE: The definition of health care provider changes in this section and now includes a dentist.

D1 & D3: We want to know if the participant remembers being told by a health care provider (doctor, dentist, nurse, nurse practitioner or physician's assistant) that she had the conditions listed in **Questions D1** and **D3** since her (MONTH) study visit. The words listed in parentheses in the form may be read to the participant to clarify the condition. To avoid biasing the interview, **do not define further.**

Circle “1” (YES) only if the condition named was diagnosed in those words by a health care provider (doctor, dentist, nurse, nurse practitioner or physician's assistant).

Skip to the next condition if the participant answers “NO,” “DON'T KNOW” or declines to answer.

- D1. Circle “1” (YES) if the participant has been specifically told by a health care provider that she had “shingles” or “herpes zoster.”
 - b. Ask the participant if she has had two or more separate areas with shingles at the same time.
- D3. Circle “1” (YES) if the participant has been specifically told by a health care provider that she had “Candida or thrush,” a Candida/yeast infection inside her mouth (oral candidiasis). If response is “NO,” skip to **Question E0**.

D1a & D3a:

Ask “a” only for responses of “YES” to **Questions D1** and **D3**. Enter the number of different times in the past six months that the participant had the specific condition reported in **Questions D1** and **D3**. **PROBE:** “*Please estimate as best you can.*” If the participant has difficulty totaling the number of times she had each condition, but can provide the number of times she had it each month, the interviewer should calculate the six-month total based on the participant’s response.

SECTION E: AIDS DEFINING ILLNESSES

- E0. The interviewer should enter the participant’s current HIV status. If she is HIV-negative, skip to **Question E23**.
- E1–E21: We are interested in knowing whether the participant has been told by a health care provider (doctor, dentist, nurse, nurse practitioner or physician assistants) that she had any of these AIDS-defining illnesses since her (MONTH) study visit. As of visit 26, **Questions E1** through **E21** will be asked only of seropositive women.

WE ARE INTERESTED ONLY IF THE DIAGNOSIS WAS MADE BY A HEALTH CARE PROVIDER AND NOT IN THE PARTICIPANT'S PERSONAL BELIEF THAT SHE HAD ANY OF THESE CONDITIONS.

If the participant is unable to recognize the medical terminology, do not offer any definitions other than those in parentheses; circle “2” for “NEVER HEARD OF IT.” **DO NOT LEAVE ANY QUESTIONS BLANK.** We believe if a participant was told by a health care provider

that she had one of these illnesses, she would then recognize it. Circle “1” (YES) for each illness in **Questions E1** through **E21** that the participant reports was diagnosed by a doctor, dentist, nurse, nurse practitioner or physician's assistant. If the participant answers “NO,” skip to the next question and do not ask any subquestions.

EACH QUESTION IN THIS SECTION BEGINS WITH THE PHRASE, “SINCE YOUR (MONTH) STUDY VISIT...” HOWEVER, IN QUESTIONS E2 THROUGH E12, THE PHRASE APPEARS IN PARENTHESES. THIS IS DONE TO MINIMIZE THE NUMBER OF TIMES THE INTERVIEWER HAS TO READ THE PHRASE. WHEN THE PHRASE APPEARS IN PARENTHESES, IT IS MEANT ONLY AS A CLARIFICATION; THE INTERVIEWER SHOULD READ IT ONLY IF IT IS NECESSARY IN ORDER TO MAKE THE QUESTION MORE CLEAR TO THE PARTICIPANT.

PROMPT: IF THE PARTICIPANT RESPONDS “YES” TO ANY OF THE AIDS-DEFINING ILLNESSES IN E4 THROUGH E20, THE INTERVIEWER MUST COMPLETE THE ASCERTAINMENT TRACKING CHECKLIST.

- E1. Ask if the participant was told by a health care provider since her (MONTH) study visit that her CD4 count was less than 200 or less than 14%.
- E2. Circle “1” (YES) if the participant has had ulcers or sores lasting longer than one month that a health care provider told her was herpes simplex.
- E3. Circle “1” (YES) if the participant has had diarrhea (three or more soft or liquid stools per day) that has lasted for more than one month since her last (MONTH) study visit. If she answers “NO,” skip to **Question E5**.
- E4i–v: Circle “1” (YES) if the participant was told by a health care provider that her diarrhea was caused by any of the conditions listed. **NOTE: A “YES” answer to Questions E4i through E4v will generate ATC records for disease codes 151, 152, 153, 151, or 154, respectively.**
- E5. Circle “1” (YES) if the participant has been told by a health care provider that she had a herpes simplex infection of the lungs or esophagus. **PROBE: “The tube between your mouth and stomach.”** **NOTE: A “YES” answer to Question E5 will generate an ATC record for disease code 201.**
- E6. Ask if the participant was told by a health care provider since her (MONTH) study visit that she had PCP, pneumocystis carinii pneumonia. We specifically want to know about PCP and not other types of pneumonia – other types are asked about separately. **NOTE: A “YES” answer to Question E6 will generate an ATC record for disease code 130.**
- E7. Ask if the participant was told by a health care provider since her (MONTH) study visit that she had another type of pneumonia or a lung infection. If the participant is certain that she received a diagnosis of bronchitis only, record “NO” for the question. If she is not sure whether the diagnosis was for pneumonia, bronchitis or some other lung infection, record “YES” for the question. The definition of this condition is up to the participant. **DO NOT** explain further. If the participant responds “YES,” ask **Questions E7a–c**. If the participant responds “NO,” skip to **Question E8**.
- For example: If the participant said, “*I had bronchitis,*” then the interviewer should not include that as a pneumonia. Bronchitis is not a pneumonia.
- NOTE: A “YES” answer to Question E7 will generate an ATC record for disease code 132.**
- a. Record the number of times the participant has had pneumonia, not PCP, in the **past 12 months** that required treatment with antibiotics. **PROBE: “Please estimate as best as you can.”** If the participant has difficulty totaling the number of times she had non-PCP pneumonia in the last year, but can

provide the number of times she had it each month, the interviewer should calculate the total based on the participant's response.

- b. Record the number of times the participant has had pneumonia, not PCP, **since her (MONTH) study visit that required treatment with antibiotics**. **PROBE: "Please estimate as best as you can."** If the participant has difficulty totaling the number of times she had non-PCP pneumonia since her (MONTH) study visit, but can provide the number of times she had it each month, the interviewer should calculate the total based on the participant's response. If the participant remarks that she just answered this question, remind her that **Question E7a** asks for the number of times in the **past 12 months** while **Question E7b** asks for the number of times **since her (MONTH) study visit**.
- c. Enter the month and year given by the participant as the last time she had non-PCP pneumonia. **PROBE: "I need the month and year (for the last time) you had pneumonia."** Interviewers should have a calendar available to aid the participant in determining the date she last had non-PCP pneumonia.

E8. Circle "1" (YES) if the participant has been specifically told by a health care provider that she had Candida or thrush, a yeast infection of her esophagus. **PROBE: "The tube between your mouth and stomach."** **NOTE: A "YES" answer to Question E8 will generate an ATC record for disease code 149.**

E9. Circle "1" (YES) if the participant has been specifically told by a health care provider that she had Candida or thrush, a yeast infection of the lungs or airway, inside her trachea or bronchi. **NOTE: A "YES" answer to Question E9 will generate an ATC record for disease code 141.**

E10. Circle "1" (YES) if the participant has been specifically told by a health care provider that she had an M-A-I infection which is sometimes called M-A-C or MAC.

Definitions are provided in the question. The hyphens mean each letter needs to be pronounced separately and "MAC" without the hyphens is read as one word.

NOTE: A "YES" answer to Question E10 will generate an ATC record for disease code 170.

E11. Circle "1" (YES) if the participant has been told specifically by a health care provider that she had a Toxo infection or toxoplasmosis of the brain. Do not explain further. **NOTE: A "YES" answer to Question E11 will generate an ATC record for disease code 172.**

E12a–e: Circle "1" (YES) if the participant has been told specifically by a health care provider that she has C-M-V in any of the listed locations. **NOTE: A "YES" answer to Questions E12a through E12e will generate ATC records for disease codes 161, 163, 164 and 165, as appropriate.**

E13. Circle "1" (YES) if participant has been told specifically by a health care provider that she had meningitis related to HIV. If participant answers "NO," skip to **Question E14**. **NOTE: A "YES" answer to Question E13 will generate an ATC record for disease code 192.**

- a. Circle "1" (YES) if the participant was told by a health care provider that this was Crypto or Cryptococcal meningitis. **NOTE: A "YES" answer to Question E13a will generate an ATC record for disease code 174.**

E14. Circle "1" (YES) if the participant has been told specifically by a health care provider that she had a Cryptococcal infection in her blood or elsewhere in her body. If the participant answers "NO," skip to **Question E15**.

- a–b: Circle "YES" or "NO" for **subquestions a and b** to indicate the location of the participant's Cryptococcal infection. If she responds "YES" to having Crypto "elsewhere in your body" specify the location in the space provided. **NOTE: A "YES" answer to Questions E14a or E14b will generate ATC records for disease code 175.**

- E15. Circle “1” (YES) if the participant has been told specifically by a health care provider that she had Histo or a Histoplasmosis infection. If the participant answers “NO” or declines to answer, skip to **Question E16. NOTE: A “YES” answer to Question E15 will generate an ATC record for disease code 173.**
- a. We want to know specifically where the participant had the infection. Record the participant's response verbatim in the space provided.
- E16. Circle “1” (YES) if the participant has been told specifically by a health care provider that she had Cocci, coccidioidomycosis infection or valley fever. **NOTE: A “YES” answer to Question E16 will generate an ATC record for disease code 176.**
- E17. Circle “1” (YES) if the participant has been told specifically by a health care provider that she had wasting syndrome, or severe weight loss. If the participant answers “NO,” skip to **Question E18. NOTE: A “YES” answer to Question E17 will generate an ATC record for disease code 210.**
- a–b: We are interested in knowing whether the participant had either of these conditions for at least one month while experiencing severe weight loss (i.e., “wasting syndrome”). Read the stem question and insert the conditions listed at **subquestions a** and **b** where it says (CONDITION). Note that each condition is a separate question and should be read as such, in the order listed, in order to obtain two separate/distinct answers.
- c. Indicate if the participant was told by a health care provider that this/these symptom(s) was/were due to AIDS.
- E18. Circle “1” (YES) if the participant has been told by a health care provider that she had dementia or encephalopathy, or that she had a memory problem or confusion caused by HIV. **NOTE: A “YES” answer to Question E18 will generate an ATC record for disease code 193.**
- E19. Circle “1” (YES) if the participant has been told by a health care provider that she had an infection in the blood with bacteria called salmonella. If the participant answers “NO,” skip to **Question E20. NOTE: A “YES” answer to Question E19 will generate an ATC record for disease code 177.**
- a. Indicate if the participant has been told she had an infection in her blood more than once since her (MONTH) study visit.
- E20. Circle “1” (YES) if the participant has been told by health care provider that she had PML or progressive multifocal leukoencephalopathy, a disease of the brain. **NOTE: A “YES” answer to Question E20 will generate an ATC record for disease code 190.**

<p>PROMPT: IF THE PARTICIPANT RESPONDED “YES” TO ANY OF QUESTIONS E4–E20, COMPLETE ASCERTAINMENT TRACKING CHECKLIST.</p>

- E21. Indicate if the participant was told by a health care provider since her (MONTH) study visit that she had AIDS. If the participant says, “*Yes, I was told I have HIV,*” ask, “*Yes, but were you told that you had AIDS?*”
- E22. Ask the participant if she knows why and where her first positive HIV test was done. If she does not remember, skip to **Question E23.**
- a. Have the participant indicate the main reason she had her first HIV test done. Circle only one response.
- b. Have the participant indicate where she had her first HIV test done.
- E23. We want to know if the participant has had a biopsy since her (MONTH) study visit. If the participant responds “NO,” skip to **Question E24.**

IF THE PARTICIPANT SELF REPORTED A DIAGNOSIS OF CANCER IN QUESTIONS C1 THROUGH C15, BUT THEN IN QUESTION E23 REPORTS THAT SHE HAD NO BIOPSY, THE INTERVIEWER SHOULD ASK FOR CLARIFICATION FROM THE PARTICIPANT. FOR EXAMPLE, AFTER THE PARTICIPANT INDICATES THAT SHE HAS NOT HAD A BIOPSY, THE INTERVIEWER COULD SAY, “Did your doctor tell you that you definitely had cancer, or just that s/he suspected you might have cancer and should return for more tests?” SINCE CANCER CAN’T BE DIAGNOSED WITHOUT A BIOPSY, IF THE PARTICIPANT REPORTS THAT SHE HAD NO BIOPSY, THE INTERVIEWER SHOULD ENSURE THAT THE FORM DOES NOT INDICATE A CANCER DIAGNOSIS.

a–g: These questions ask the participant exactly where in her body she had a biopsy. If the participant reports having had a liver biopsy when asked **Question E23**, go back and record it in **Question C38c**. Do not record a liver biopsy in **Question E23**.

NOTE: A “YES” answer to **Question E23a** will generate an ATC record for disease code 611.

A “YES” answer to **Question E23b** will generate an ATC record for disease code 612.

A “YES” answer to **Question E23c** will generate an ATC record for disease code 613.

A “YES” answer to **Question E23d** will generate an ATC record for disease code 614.

A “YES” answer to **Question E23e** will generate an ATC record for disease code 617.

A “YES” answer to **Question E23f** will generate an ATC record for disease code 615.

A “YES” answer to **Question E23g** will generate an ATC record for disease code 616.

PROMPT: IF THE PARTICIPANT RESPONDED “YES” TO ANY OF QUESTIONS E23a–g, COMPLETE AN AIDS AND CANCER SPECIMEN RESOURCE ASCERTAINMENT TRACKING CHECKLIST (ACSR ATC) FOR EACH REPORTED BIOPSY AND OBTAIN MEDICAL RECORD RELEASE.

- E24. Indicate if the participant has been hospitalized since her (MONTH) study visit. If the participant answers “NO,” skip to **Question E26**.
- Record the number of times the participant reports she has been hospitalized since her (MONTH) study visit. **PROBE: “Please try and remember as best you can.”** If the participant has difficulty totaling the number of times she has been hospitalized since her (MONTH) study visit, but can provide the number of times she was hospitalized each week or each month, the interviewer should calculate the total based on the participant’s response.
 - Indicate if the participant continued taking her antiretroviral medications while she was hospitalized. If the participant does not take antiretroviral medications, circle “3” for “not applicable.” If the participant was hospitalized more than one time, circle “2” for “no” if she discontinued taking her antiretroviral medications for even one of the times she was hospitalized.
- E25 a-g. Record what the participant indicates is/are the best reason(s) for her hospitalization(s). “YES” may be circled for more than one response. If the participant answers “other,” record her answer verbatim in the space provided.
- E26. Record the time module was completed.