

## Guidelines for Completing Visit 36.5/76 Section 4 (MACS Questionnaire)

### **General Instructions:**

1. Use a number 2 pencil and completely fill in the bubbles. If you need to erase, make sure the mark is erased completely.
2. Ask the questions as they appear on the form. For some questions, prompting or further explanation is allowed. These are specified in the guidelines next to the corresponding question number.
3. For dates that appear on the form, if the participant cannot remember the exact month (and day), probe for the season. (Use "15" for the day if specific day cannot be recorded).

Summer	=	July	=	07
Fall	=	October	=	10
Winter	=	January	=	01
Spring	=	April	=	04
Don't know month	=	June (midpoint)	=	06

4. For open-ended questions, keep lists of responses. Interviewers should write responses, exactly in the words of the respondent.
5. Be specific where possible.
6. Follow the skip patterns as they appear on the form.
7. Record the time the interview began and ended.

### **Question 1: Medical Conditions Indicative of AIDS**

These conditions refer to illnesses, which have been diagnosed since the participant's recruitment visit. If the participant does not remember if he reported an earlier diagnosis, record it.

For each "Yes" in *a*, complete part *b* and obtain a signed medical release. **Report to CAMACS on an Outcome Reporting Form.**

**1.E** - Mark the circle next to each organ in which CMV was diagnosed. If in an organ other than eyes, lung or colon, mark "Other" and record the locations in the specify box. If participant does not know or was not told the location of CMV, then mark "Other" and record "Don't Know" in specify box. A serologic test, "blood" test, or "antibodies for CMV," by itself does not define CMV disease and should not be recorded.

**1.G** - Specify the type of lymphoma. If the lymphoma was not primary brain lymphoma or non-Hodgkin's, mark "Other" and specify in box. If participant reports that he was told that the type of lymphoma is unknown, then mark "Other" and record "Unknown" in specify box. If participant does not know or was not told what type of lymphoma he has, then mark "Other" and record "Don't Know" in specify box.

A box that asks for the name and address of the physician who diagnosed the condition(s) is provided to assist in the abstraction of medical records

### **Question 2:**

***The next few questions are about Tuberculosis, or TB for short. To see if a person has tuberculosis a doctor or nurse will give a skin test – sometimes called a PPD test. If the skin test shows the person has been exposed or infected with tuberculosis, more tests are done to see if they are sick from the tuberculosis. A person might get a chest X-ray or be asked to cough into a machine. If they are sick then we say they have "tuberculosis disease". Sometimes this is called "active" or "infectious tuberculosis". Usually, if a person has tuberculosis disease, people who lived or worked with the person will be tested for tuberculosis too.***

If the participant does not know if the PPD was positive, do not leave blank. Ask if physician told participant it was positive or if further testing was performed. If no to the above, then mark "No". Default is "No".

**Question 3:**

**3.B&C** - Ask whether the tuberculosis, or TB, was diagnosed in the lungs or outside the lungs. Mark the appropriate circle. If participant does not know or was not told the location of TB, leave blank. If active TB is reported, obtain a medical release and report to CAMACS on an Outcome Reporting Form.

**Question 5:**

Specify the site and type of cancer. Cancer coding lists (Appendix 1) will be used to code this information.

**Question 7:**

This question refers to radiation other than x-rays by the dentist or for diagnosis purposes.

**Question 8:** Hospitalization

These questions refer to staying "overnight" or being admitted to the hospital. It does not include visits to the emergency room or hospital-based clinics for acute care.

**8.B** - Start with the most recent hospitalization; i.e. the one closest to the current date, and then the one before that, etc.

Example: Participant is interviewed on 05/01/96. He was seen at the emergency room on 03/18/96 and was hospitalized on 1/10/96 and 4/15/96.

Question 8.B.(1)a would be: 04 = A = April  
5 = 15th day  
96 = 1996

Question 8.B.(2)a would be: 01 = J = January  
10 = 10th day  
96 = 1996

The emergency room visit would not be coded here.

Record the conditions or problems resulting in the hospitalizations. If AIDS-related go to *Q.1- Q5*, and code where appropriate. If participant had reported being diagnosed with an AIDS condition (*Q.1*) or cancer (*Q.5*), but did not report a hospitalization, ask participant if he had to be hospitalized for the condition and record.

Mental health professional may be a psychiatrist, psychologist, social worker or other health care provider in mental health setting. Please note that a medical release does not need to be obtained if the participant answers “yes” to Question 8.

**Question 9:**

If the participant was adopted and/or indicates that he has no knowledge of family history, the interviewer should mark “Don’t know”

**9.B** If answered yes, that a family member had cancer, mark “Yes” and ask each of the types. Mark “Yes” for the type(s) they had and “No” for the ones they did not have. If the participant specifies another type of cancer (“Other”), mark “Yes” and record in the participant’s own words.

**Question 10:**

If participant was diagnosed with cancer (“Yes” to Q.5) and responds that he did not have a biopsy, refer back to the cancer and re-ask the question. Record all sites which were biopsied and the diagnoses that were made. Make sure to include the date of the biopsy. These responses will be coded later (Appendices 2 and 3).

**Question 14:**

Ask if participant has ever been told he had the condition in a-v. If “yes”, ask if it was within the past 6 months. If it was within the last 6 months, mark “yes, *within the last 6 months*”. If it was not within the last 6 months, mark “yes, *but not in last 6 months*”. If any conditions in J-R or T are reported, obtain a medical release.

**14.A** – If participant has had shingles/herpes zoster, ask the month and year the most recent episode began. If it was before 1991, write in the correct year but bubble in ‘91’.

**14.B** – If participant has had thrush, ask the month and year the most recent episode began. If it was before 1991, write in the correct year but bubble in ‘91’.

**14.Q** – If participant did not have arthritis, mark “No” and leave specific types blank. If participant had arthritis, mark “Yes” and ask each of the types. Mark “Yes” for the type(s) that he had and “No” for the ones he did not have. If the participant specifies another type of arthritis (“Other”), mark “Yes” and record in the participant’s own words. If the participant does not know what type of arthritis, mark the bubble next to “Don’t know what type” and mark the others type as “No”.

**14.S** – If participant did not have any kind of hepatitis, mark "No" and leave specific types blank. If participant had hepatitis, mark "Yes" and ask each of the types. Mark "Yes" for the type(s) that he had and "No" for the ones he did not have. At least one needs to be specified if participant had hepatitis. If the participant does not know the type of hepatitis, mark the bubble next to "Don't know" and mark the other types as "No". If the participant specifies another type of hepatitis ("Other"), mark "Yes" and record in the participant's own words. Probe how the diagnosis was made. This type should be reviewed by the coordinator for possible recoding. If the "other" response does not represent a recognizable hepatitis type, then the "Don't know" should be marked "Yes".

**14.T** – If the participant answers "yes" to being diagnosed with liver disease, then a medical release must be obtained. A participant reporting hepatitis does not necessarily have liver disease. Liver disease is a late stage outcome for hepatitis. However if the participant reports liver cancer, liver disease should be marked "yes". Liver disease should be reported to CAMACS on an Outcome Reporting Form.

**14.U and V** – If the participant received a Hepatitis vaccine but does not know which type, inquire how many shots the vaccine consisted of and what was the time frame between shots. **The Hepatitis A vaccine consists of 2 shots, 6 months apart. The Hepatitis B vaccine consists of 3 shots, the second given 1 month after the first and the third given 6 months after the first shot.** If the participant still does not know which vaccine he received, mark both as "No".

#### **Question 15:**

If participant had a neurological examination, the question of whether a diagnosis was made needs to be answered. If there was a diagnosis, record the diagnosis in the specify box. The response is to be coded later (Appendix 4).

#### **Question 16:**

Parts a through o must be answered. If answer is yes, ask what was the diagnosis and record response in the specify box. **If more than one diagnosis per area, record additional diagnoses in the "other" area.** The response will be coded later using ICD-9 codes.

**16.o** – If participant had been to a medical care provider for any other condition (other than conditions previously asked in *Q.1-16n*), the question of what was the diagnosis needs to be answered. Record diagnosis in the specify boxes. Coding will be performed later using ICD-9 codes.

#### **Question 17:**

Each item in *Q.17.A* needs to be completed. If participant reports any type of herpes simplex ("Yes" to any item in *17.A*), *B* and *C* need to be answered.

**Question 18:**

Items *A, B, F-I* need to be completed. If participant reports having gonorrhea, complete items *C - E*.

**Question 19:**

**19.A.** Complete all items. For each "Yes" in *a*, complete *b* and *c*.

**19.B.** Ask participant each question. For each "Yes" ask them to indicate the severity on a scale of 0 (none) to 10 (severe) for each side. Example: if the participant experienced a level of pain around 7 in his left foot/leg, then code "0" for the right and "7" for the left.

***Note: If the participant is HIV negative, some of the following questions will not apply. If that is the case, indicate to the participant he should answer "no" for those questions that do not apply.***

**Question 20:**

If the participant answers "no" to part A, indicating he has not had a drug resistance test, then skip to Q21. However, if he has had the test, continue with parts B and C. For part C, if his treatment has changed, but his doctor did not indicate the reason(s) for a change in therapy, then mark "Don't know".

**Genotypic VS Phenotypic:** Genotypic assays determine changes in the HIV genome only (i.e. changes in the viral protein sequence) whereas phenotypic assays actually measure HIV resistance. Phenotypic looks at the ability of the virus to grow in the presence of a drug. It is much more time-consuming and expensive.

**Question 21: AIDS Medications**

Question 21 refers only to medications used to fight AIDS, HIV, opportunistic infections, or stimulate the immune system. Medications that appear on the drug lists but were used for other health reasons should not have a corresponding drug form completed. If participant is not taking any drugs for HIV, AIDS or opportunistic infections, go to Q. 21.A.

**21.A** – This question obtains information on why the participant is NOT taking HIV-related medication. Mark every reason the participant responds "yes" to by filling in the corresponding bubble. If he is not taking medication because he is not infected with HIV, skip to Q22. If reason is not listed, fill in other reason bubble and write reason in the specify box. Skip to Q22.

**21.B** – Show the participant the current **LIST 1** and the medication photo cards for *Q.21.B(1)*. If the participant has problems with his vision, read the list of medications. For each medication listed ask 'a', if the participant has **ever** taken the

medication. If his response is “yes”, proceed to ‘b’ and ‘c’. ***If the participant answers “NO” to ‘a’, move on to the next drug on the list.*** The listing on the questionnaire is not complete. However, it does contain currently used medications to the best of our knowledge. **Refer to the complete drug lists.** This list is updated every six months.

For EACH drug reported ***as taken in the last 6 months***, complete a **DRUG FORM 1**. Multiple drugs per bubble on the list refer to **blinded clinical trials** only, where the participant does not know whether he is taking a placebo or the actual drug(s) listed. If the participant is alternating antiretrovirals, is unblinded to treatment in a trial, or is taking multiple antiretrovirals on the same day, mark each drug and complete a separate **DRUG FORM 1** for each medication.

#### **EXAMPLES for Participant “X”:**

X is taking AZT, 3TC and Indinavir. Bubble AZT, 3TC and Indinavir; complete a separate Drug Form 1 for each drug.

X is in an AZT/3TC/nevirapine blinded trial, but he does not know whether he is taking 3TC or a placebo (i.e. he is blinded to the treatment). Bubble AZT, 3TC and nevirapine. Complete a separate Drug Form 1 for each drug. The Drug Form 1 for 3TC will only include Q1.

X is in an AZT/3TC/protease inhibitor trial, but he knows that he is taking AZT, ddI, and a protease inhibitor rather than a placebo (i.e. he is unblinded to the treatment.) Bubble AZT, ddI, and the name of the protease inhibitor and complete a separate Drug Form 1 for each drug (i.e. 3 drug forms)

For any other anti-viral medication used by the participant against HIV-1 but is not on the list, mark “*Other anti-viral*” and record drug in box along with the drug code. Check **AIDS MEDICATIONS LIST 2** to see if it is on this list. If so, record in *21.C(2)*. Else, complete a **DRUG FORM 1**. Bring this to the attention of clinic coordinator/director. If the drug is not on the coding list, the center's director should contact the coordinator at CAMACS.

**21.B(2)** – Mark every reason the participant responded yes to by filling in the corresponding bubble. If reason is not listed, fill in other reason bubble and write reason in the specify box. Skip to Q21.C.

**21.B(3)** – This question assesses whether the patient took a break of at least 2 consecutive days from their antiretroviral medications, and if so, for how long. It also captures how many times they missed and if any of the breaks were prescribed by a physician. If a participant missed at least 2 consecutive days of all prescribed antiretroviral therapy at three different times, but only one of those times was prescribed by a physician, the response to this question “Did your physician

prescribe or agree to any of these?” would be “yes”. If the participant had multiple lapses in therapy use, ask them to report the length of the most recent one.

**21.C** – Give the participant **LIST 2** for *Q.21.C*. If the participant has problems with his vision, read list of medications. Record each drug participant responds with a “Yes”, by completing the bubble next to the drug. For EACH drug reported, complete a **DRUG FORM 2**.

**21.D** – This question should be used to record medications used against HIV, AIDS and opportunistic infections not listed in *B* or *C*. Be sure to check Drug Lists 1 and 2 for a code before recording it in this section. The actual name of the drug should be written in the specify box. However, these medications will be coded by their function. Since many of these drugs are multi-functional ask the participant specifically why he is taking the medication and include this in the specify box. Maintain log of written responses. Note that if the participant indicates he is taking Acyclovir as part of his HIV antiviral regimen, then it should be coded here as 527 (other medications).

**Question 22:** Other Medications

This question should be used to record medications, other than those against HIV and AIDS, which are prescribed by a physician. Record the name of the drug in *b*. If unsure about the spelling, ask the participant. Maintain a log of written responses.

**22.10** - Acyclovir prescribed for herpes should be recorded here. If the participant responds “Yes”, he should answer no/yes for chronic and episodic herpes. If the patient claims that he is taking Acyclovir as part of his HIV antiviral therapy, then it should be coded in Q21.D (other medications) as 527.

**22.12** - Record any cholesterol, lipid lowering medications. The cholesterol and lipid lowering meds are part of the 800 series and can be found in the codebook and drug lists.

**22.13** - Record any diabetic medications. The diabetic meds are part of the 900 series and can be found in the codebook and drug lists.

**22.14** – Record any hepatitis medications. The hepatitis medications are part of the 700 series and can be found in the codebook and drug lists.

**22.15** - Record other medications used in the last 6 months in *b*, with the reason for its use.

**Question 23:**

**23.A** – A vaccine against HIV-1 can include vaccines which prevent infection with HIV or therapeutic vaccines (those which prevent progression of the infection.)



**23.B** – If A is “yes”, record name of trial in specify box. Coding of trial will be done later using codes from the HIV vaccine lists. In TABLE 1 use the “Site of Study or AVEG/HVTN\*\* Protocol number(s)”. There are 4 spaces allowed for coding. Use only numbers in the code box. For example, many of the codes for AACTG studies start with an “A”. The “A” should be excluded.

**23.C** – Record all available information about sponsor and location of the trial.

**Question 24:** Health Insurance

HMO is a health maintenance organization, such as Kaiser Permanente, Harvard Health, Prudential HMO.

If privately insured through their employment and not by an HMO, it is group private insurance.

If “Other” (Item 8) type of medical coverage, probe to see if purchased individually or as part of a group. At least try to see if it is a private insurance. Specify name and whether it is a private insurance in the specify box. It may be coded as “3” for private but unknown whether it's individual or group. A “PPO” written in “Other” should be coded under “Private, Group coverage”.

Examples of typical responses under “Other” and their correct reclassification:

COBRA	OTHER = 3 (this means the participant has private insurance but we don't know if it's group private or individual private)
Major Medical	OTHER = 3
Employer	OTHER = 3
Crisis insurance	OTHER = 3
Hospitalization	OTHER = 3
Catastrophic policy	OTHER = 3
Self-insurance	GPIC (group private insurance)
Union policy	GPIC
AARP	GPIC
Group insurance	GPIC
Military	VABEN (Veteran's Administration/Armed Forces coverage)
Kaiser	HMOC (HMO)
Medigap	MCARE (Medicare) and OTHER = 3

If participant does not have health insurance, "No" is answered for each item, confirm and then go to **Q.24.B**.

**24.B** – This question captures those participants that have any form of medication coverage, even if they do not have other medical coverage. If the participant answers "no" to all of the responses in part A and B, then they should skip to Q28, otherwise they should continue with question 25.

**Question 25:** Change of Insurance

Do not ask this question if the participant does not have any health insurance. If participant did not change his insurance coverage in the last 6 months, do not ask *B-D*. This question is trying to assess what factors contributed to the patient's health plan change. If the participant dropped his own insurance to become insured through his partner, we would like to know the main reasons that influenced him to take this action. The interviewers should not accept the answer of "I wanted to change to my partner's plan". They should ask the participants why they dropped their former coverage.

**25.C** - Each item should be asked and responded with a "No" or "Yes". If "Yes" to only 1 item, go to *Q.26*.

**25.D** - Only to be answered if more than 1 "Yes" to *Q.25.C*. Only accept one response as the primary reason. If the participant states more than one, restate the question, asking the participant for 1 primary reason.

**Question 26:**

Do not ask if participant is not currently insured. Similar to question 25, this question is trying to assess what factors contributed to the patient's health plan change. If the participant chose his new insurance through his partner, we would like to know the main reasons that influenced him to take this action. The interviewers should not accept the answer of "I wanted to change to my partner's plan". They should ask the participants why they chose this new insurance plan.

**Question 27:**

Do not ask if participant is not currently insured.

Allow the participant to answer with a number from 1 to 7. Mark the circle next to the responded number. It is not required for participant to have used his coverage to rate his satisfaction.

**Question 29:**

If none of the items apply, be specific when recording other source of usual medical care in box. Keep a log of written responses. If participant replies with more than 1 source, state that you will ask where he went but here you need to know the 1 place where he usually goes for medical care. See instructions for Q.30 for further probing and classification.

**Question 30:**

Outpatient medical care does not include hospital admissions. Clinics within hospitals should be recorded as clinic.

When a participant responds that he has gone to a specialist, this should be marked as doctor (DOCOV), e.g. allergist, eye doctor, dermatologist, neurologist.

Urgent care facilities are included in the doctor's office response.

Whenever a participant says he has been to the lab, the interviewer should probe to see if the lab work had been conducted as part of another doctor's or clinic visit. If so, then it can just be marked as the one doctor's visit. However, if it is a separate visit or location (even on the same day) then it should be marked as "OTHER". When recoding (i.e., it's too late to probe), it should remain as "OTHER".

Miscellaneous services are appropriate for the other category, including chemotherapy, pentamidine, physical therapy.

If a participant says "VA", the interviewer should probe as to whether this was a visit to the participant's own doctor there or if it was a clinic appointment. Absent this information, recode it as any clinic (CLOV).

Otherwise, examples of coding:

allergist	DOCOV (Doctor's office)
podiatrist	DOCOV
dermatologist	DOCOV
eye doctor	DOCOV
ENT surgeon	DOCOV
optometrist	DOCOV
x-ray	OPOV (other outpatient care)
blood tests	OPOV
physical therapy	OPOV
resp therapy	OPOV
speech therapy	OPOV
CT scan	OPOV
VA	CLOV (any clinic)

student health clinic

CLOV

**Question 32:**

Out-of-pocket expenses include any charges not paid for by insurance such as deductibles, co-payments, charges above the allowable limits or costs of services not covered by insurance. These expenses refer to the amount that was paid, not how much may still be owed. Round to the nearest dollar. If total expenses were less than \$1, code as "0".

If the participant responds with "*Don't know*", ask participant to make his best estimate. If he still doesn't know, than mark the bubble next to "*Don't Know*". If the participant doesn't wish to answer the question, mark "*Refused*".

**Question 33:**

**33.A** - If the participant responds "NO," they DID NOT not seek care or obtain prescriptions they thought they needed, skip to Q34. If the participant responds "YES," they DID not seek care or obtain prescriptions they needed, go to Q33.B.

**33.B(1)** - Record in participant's own words his reason for not seeking medical care if other than financial. Maintain a log of written responses.

**33.B(2)** - Record in participant's own words his reason for not seeking dental care if other than financial. Maintain a log of written responses.

**33.B(3)** - Record in participant's own words his reason for not obtaining prescription medications if other than financial. Maintain a log of written responses.

After Question 35, the interviewer should STOP. The rest of the interview should be administered via ACASI. Following the ACASI, complete items 65 – 67. If in the rare occurrence that the ACASI is not available, the interviewer-administered version should be completed. Guidelines for it are provided below.

**Question 38:**

If the participant changed employment because of HIV, ask each item and record "No" or "Yes" response. If all *items 1-7* are "No", record participant's reason in specify box.

**Question 39:**

**39.A** - If participant never smoked cigarettes, mark "No" and go to Q.40.

**39.B & C** - If participant currently smokes cigarettes ("Yes" to Q.39.C), skip to Q39.E. If participant does not currently smoke ask Q39. If the participant only smokes occasionally, skip to Q.39.F.

**Question 40:**

If participant did not drink any alcoholic beverages in the last year, skip Q.40.B&C. Mark only 1 bubble in Q.40.B. & Q40.C.

**Question 41:**

If the participant had any sexual activity in the last 2 years, continue to Q42. If no sexual activity, skip to Q50.

**Question 42:**

If the participant had any sexual activity with a woman in the last 2 years continue to Q42. If not, skip to Q46.

**Question 43:**

If the participant had any sexual activity with a woman in the last 6 months continue to Q43. If not, skip to Q46.

**Question 44:**

For A and B, if response is 1000 partners or more, code "999".  
If participant did not report intercourse with women in the last 6 months, SKIP to Q45.10.

**Question 45:**

If participant had only 1 female partner (sum of Q.44.A and Q.44.B = 1), use *column a*; *b* should be blank for all items. If he had more than 1 partner (sum of Q.44.A and Q.44.B > 1), use *column b*; *a* should be blank for all items. For *column b*, if the participant reports 1000 partners or more, code as "999".

If participant responds as not engaging in any of the behaviors described in sub questions 1 – 9, but did report at least 1 intercourse partner, refer back to the intercourse question, read the definition of intercourse and re-ask sub questions 1 – 9.

**45.1** - If oral intercourse with women is "No" (single partner) or "0" (multiple partners), do not ask items 2&3.

**45.4** - If no vaginal intercourse with women ("No" if 1 partner, "0" if multiple partners), do not ask item 5&6.

**45.7**- If anal intercourse with women is "No" (single partner) or "0" (multiple partners), do not ask item 8&9.

**45.10** - If answered "yes" to any sexual activity with a woman in the last 6 months, Q45.10 must answered.

**45.11**- If answered "yes" to any sexual activity with a woman in the last 6 months, Q45.11 must answered.

**Question 46:**

If the participant had any sexual activity with a man in the last 2 years continue to Q47. If not, skip to Q50.

**Question 47:**

If the participant had any sexual activity with a man in the last 6 months continue to Q48. If not, skip to Q50.

**Question 48:**

For A and B, if response is 1000 partners or more, code "999".  
If participant did not report intercourse with men in last 6 months, SKIP to Q49.13.

**Question 49:**

If participant had only 1 male partner (sum of Q.48.A and Q.48.B = 1), use *column a*; *b* should be blank for all items. If he had more than 1 partner (sum of Q.48.A and Q.48.B > 1), use *column b*; *a* should be blank for all items. For *column b*, if the participant reports 1000 partners or more, code as "999".

If participant responds as not engaging in any of the behaviors described in sub questions 1 – 12, but did report at least 1 intercourse partner, refer back to the intercourse question, read the definition of intercourse and re-ask sub questions 1 – 12.

**49.1** - If oral insertive intercourse is "No" (single partner) or "0" (multiple partners), do not ask item 2&3.

**49.4** - If no anal insertive intercourse ("No" if 1 partner, "0" if multiple partners), do not ask item 5&6.

**49.7** - If oral receptive intercourse is "No" (single partner) or "0" (multiple partners), do not ask item 8&9.

**49.10** - If no anal receptive intercourse ("No" if 1 partner, "0" if multiple partners), do not ask item 11&12.

**49.13** - If answered "yes" to any sexual activity with a man in the last 6 months, Q49.13 must answered.

**49.14** - If answered "yes" to any sexual activity with a man in the last 6 months, Q49.14 must answered.

**Questions 50 - 56:**

These questions are to summarize the participant's past sexual activity.

**Question 50:**

If the participant "never" had sexual intercourse with a woman, skip to Q53. If he had it "6-10 years ago" or "more than 10 years ago", skip to Q52. If he answers "within the last month" or "within the last year...", check to make sure this is consistent with answers given for Q42, Q43, and Q44.

**Question 53:**

If the participant "never" had sexual intercourse with a man, skip to Q56. If he had it "6-10 years ago" or "more than 10 years ago", skip to Q52. If he answers "within the last month" or "within the last year...", check to make sure this is consistent with answers given for Q46, Q47, and Q48.

**Question 57:** Recreational Drugs (does not include drugs that may have been prescribed by a physician).

Ask part a for all drugs, if "yes", ask b. If b is "yes", ask part c.

For other kinds of drugs, ask the participant for specific name. If given a slang name, ask if known by another name. Record both the slang name and other name in the same specify box. These will be coded using codes in Appendix 5. ***For "other kinds of street/club drugs", if a is "yes", ask b & c for each additional drug.***



**Question 58 – 64: IV drug Use**

58.A. –If the answer to Q58.A is “no”, SKIP to Q64.

58.D – Ask for all four drugs. If answer is none enter ‘00’. If answer is 99 or greater enter ‘99’.

**Question 59:**

If answer is “yes”, must ask questions 60A & B.

**Question 61:**

If answer is “yes” to A, must answer B & C.

**Question 63:**

If answer is “yes” to A, must answer B & C.

**Question 65:**

***All participants***, those using the ACASI as well as those that are not, should answer this question.

**Question 66:**

Record the date and time the interview ended.

**Question 67:**

Sign your name and record the number assigned to you.

## Appendix 1: Cancer Site Codes

### 1400 Oral/Pharynx (not otherwise specified) (NOS)

- 1409 Lip
- 1410 Tongue
- 1420 Salivary Gland
- 1460 Tonsil
- 1470 Nasopharyngeal

### 1500 Digestive System (not otherwise specified)

- 1510 Stomach
- 1520 Small Intestine
- 1530 Colon
- 1540 Rectum
- 1543 Anus/Anorectal
- 1550 Liver
- 1570 Pancreas

### 1600 Respiratory System and Intrathoracic Organs (not otherwise specified, see below) (including nasal cavity, sinuses, middle and inner ear, larynx, pleura, thymus, heart and mediastinum)

- 1620 Lung/Bronchus
- 1650 Other Respiratory

### 1700 Bones/Joints

### 1710 Soft Tissue

### 1730 Skin (not otherwise specified, to Kaposi's sarcoma or melanoma)

- 9140 Kaposi's sarcoma
- 8720 Melanoma

### 1850 Prostate

### 1870 Male Genitals (not otherwise specified)

- 1860 Testes
- 1874 Penis

### 1880 Bladder

1890 Kidney  
1900 Eye/Orbit  
1910 Brain  
1920 Other Nervous System  
1930 Thyroid  
1940 Other Endocrine Glands  
9590 Non-Hodgkin's Lymphoma  
    9710    Brain Lymphoma  
    9750    Burkitt's Lymphoma  
9650 Hodgkin's Disease  
9730 Multiple Myeloma  
9800 Leukemia (not otherwise specified)  
    9821    Acute Lymphocytic Leukemia  
    9823    Chronic Lymphocytic Leukemia  
    9861    Acute Myelocytic Leukemia  
    9863    Chronic Myelocytic Leukemia  
    9890    Monocytic Leukemia  
1950    Cancer (not otherwise specified)

## **Appendix 2: Tissue Biopsy Site**

- 01 = Adrenals
- 02 = Blood
- 03 = Bone marrow
- 04 = Brain
- 05 = Cerebrospinal fluid
- 06 = Gastro-intestinal tract
- 07 = Kidney
- 08 = Liver
- 09 = Lung
- 10 = Lymph nodes
- 11 = Myocardium
- 12 = Nerve, peripheral
- 13 = Oral cavity
- 14 = Prostate
- 15 = Skeletal muscles
- 16 = Skin
- 17 = Spinal Cord
- 18 = Spleen
- 98 = Other
- 99 = Biopsy, unknown site

## **Appendix 3: Diagnosis of Tissue**

- 0 = Don't know
- 1 = Tuberculosis
- 2 = Lymphoma/CA
- 3 = Toxoplasmosis
- 4 = (Benign) reactive hyperplasia
- 5 = Benign
- 6 = Non-diagnostic/non-specific/inconclusive/indeterminate/normal/negative/nothing found
- 7 = Vasculitis
- 8 = Granuloma
- 9 = Other
- Blank = Missing

## Appendix 4: Neurological Condition

100 = HIV cran neur  
101 = Pain sens neur  
102 = Infl demy neur  
103 = Mono multi  
105 = Other HIV neur  
110 = Non-HIV cran neur  
111 = Entrap neur  
112 = Toxic neur  
113 = Diabetic neur  
114 = Other non-HIV neur  
120 = Vacuol myel  
121 = Inf causes of myel  
122 = Met/nutr causes  
123 = Other myel  
130 = HIV polymyo  
131 = Toxic myop  
132 = Other myop  
140 = Neurosyph  
141 = HIV asepy men  
142 = Poss demen  
143 = Poss demen (conf)  
199 = Oth neurologic dis  
Blank = Missing

## **Appendix 5: Street Drug**

1 =

2 = "Downers" including barbiturates as yellow jackets or reds, tranquilizers like Valium, Librium, Xanax or other sedatives or hypnotics like Quaaludes

3 = Methadone or other opiates/narcotics like Demerol

4 = PCP, angel dust, psychedelics, hallucinogens, LSD, DMT, mescaline, Ketamine or special K

5 =

6 = Ethyl Chloride as inhalant

7 = GHB

9 = Other