

Subject ID#: (preprinted)

Date: _____
Month / Day / Year
Visit #: 2

MHCS-II Participant Follow-Up Survey
(Form 60)

Sponsored by:
National Cancer Institute
Viral Epidemiology Branch

Conducted by:
Research Triangle Institute
Washington, DC

**The information entered on this form will be handled
in the strictest confidence and will not be
released to unauthorized personnel.**

Thank you for participating in this important study. Your answers will greatly contribute to our research on hemophilia. Some questions ask for personal information and if you are uncomfortable with a particular item, you are not required to answer it. However, be assured that all of your answers will be kept highly confidential.

For some questions, place a check (✓) on a line, and for others you will write a number. Please feel free to write comments where you feel they are needed to explain your answer. Depending on how you answer a question, you may be asked to skip to another part of the survey. If you need any assistance, please feel free to ask.

Section A. Medications

A1. HIV Medications

We would like information about the HIV medications **you currently use**. Place a check next to each drug you are using and tell us how long you have used it (i.e., the number of weeks, months, years). If you used something not listed, write it in on the line.

EXAMPLE:

✓ _____ amprenavir (Agenerase) 7 months

- I AM NOT HIV+ → Go to A2
- I DO NOT CURRENTLY USE HIV/AIDS MEDS → Go to A2

<u>Current Antiretrovirals</u>	<u>Length of Time Used (e.g., 2 weeks)</u>
_____ abacavir (Ziagen) ²²¹	_____
_____ amprenavir (Agenerase) ²²²	_____
_____ combivir (AZT/3TC) ²²³	_____
_____ delavirdine (Rescriptor) ²²⁴	_____
_____ didanosine (ddI, Videx) ²²⁵	_____
_____ efavirenz (Sustiva) ²²⁶	_____
_____ hydroxyurea (Droxiz) ²²⁷	_____
_____ indinavir (Crixivan) ²²⁸	_____
_____ lopinavir/ritonavir (Kaletra) ²²⁹	_____
_____ lamivudine (3TC, Epivir) ²³⁰	_____
_____ nelfinavir (Viracept) ²³¹	_____
_____ nevirapine (Viramune) ²³²	_____
_____ ritonavir (Norvir) ²³³	_____
_____ saquinavir (Fortovase, Invirase) ²³⁴	_____
_____ stavudine (d4T, Zerit) ²³⁵	_____
_____ tenofovir (Viread) ¹⁰⁹	_____
_____ trizavir (AZT/3TC/abacavir) ²³⁶	_____
_____ zalcitabine (ddC, Hivid) ²³⁷	_____
_____ zidovudine (AZT, ZDV, Retrovir) ²³⁸	_____

Prophylaxis medications (for AIDS-related infections)

	<u>Length of Time Used (e.g., 2 weeks)</u>
_____ acyclovir (Zovirax) ²³⁹	_____
_____ aerosolized pentamidine (Nebupent, Pentam) ²⁴⁰	_____
_____ atovaquone (Mepron) ¹⁴¹	_____
_____ azithromycin (Zithromax) ⁸²	_____
_____ clarithromycin (Biaxin) ²⁴²	_____
_____ dapsone (DDS) ²⁴³	_____
_____ famciclovir (Famvir) ²⁴⁴	_____
_____ fluconazole (Diflucan) ¹⁶²	_____
_____ ganciclovir (Cytovene, DHPG) ²⁴⁵	_____
_____ rifabutin (Ansamycin, Mycobutin) ²⁴⁶	_____
_____ trimethoprim/sulfa (Bactrim, Septra) ¹⁶⁰	_____
_____ valacyclovir (Valtrex) ²⁴⁷	_____
Other HIV/AIDS drug 1 _____	_____
Other HIV/AIDS drug 2 _____	_____
Other HIV/AIDS drug 3 _____	_____

A2. HCV Medications

We would like to know about any HCV medications you used since your last study visit.

You were last seen for a study visit on [DATE OF ENROLLMENT].

Place a check next to each drug you used since your last visit.

DIDN'T USE ANY HCV MEDS SINCE LAST STUDY VISIT → Go to A3

_____ Intron (standard interferon) ²⁷⁵	_____ Virazole (ribavirin) ²⁸⁰
_____ Roferon (standard interferon) ²⁷⁶	_____ Rebetron (standard interferon/ribavirin combo) ²⁸¹
_____ Infergen (standard interferon) ²⁷⁷	_____ PEG-Intron (pegylated interferon) ²⁸²
_____ Standard interferon (brand unknown) ²⁷⁸	_____ Pegasys (pegylated interferon) ²⁸³
_____ Rebetol (ribavirin) ²⁷⁹	

A3. Other Prescription Medications (excluding HIV/HCV meds)

We would like to know about any other prescription medications you used since your last study visit. Place a check next to each drug you used since your last visit. If you used something not listed, write it in on the line.

DIDN'T USE OTHER PRESCRIPTION MEDS SINCE LAST STUDY VISIT → Go to A4

- | | | | |
|-------|--------------------------|-------|-----------------------------------|
| _____ | Vioxx ²² | _____ | Oxyir ⁴² |
| _____ | Celebrex ⁵ | _____ | Hydrochlorothiazide ⁸⁶ |
| _____ | Vicodin ²¹ | _____ | Prilosec ³ |
| _____ | Tylenol #3 ⁷² | _____ | Zoloft ¹⁹ |
| _____ | Percocet ⁵⁵ | _____ | Neurontin ⁴⁵ |

- Other prescription drug 1 _____
Other prescription drug 2 _____
Other prescription drug 3 _____

A4. Herbal Supplements and Other Drugs

Please tell us about any herbs or other drugs you used since the last study visit.

DIDN'T USE HERBS/DRUGS SINCE THE LAST STUDY VISIT → Go to Section B

Herbal Supplements

- _____ Alchemilla (lady's mantle)²⁴⁸
_____ Chaparral²⁴⁹
_____ Chondroitin²⁵⁰
_____ Evening Primrose²⁵¹
_____ Ephedra (ma huang)²⁵²
_____ Feverfew²⁵³
_____ Fish Oil (omega-3 or 3-fatty acids)²⁵⁴
_____ Gentian²⁵⁵
_____ Germander²⁵⁶
_____ Ginkgo²⁵⁷
_____ Ginseng²⁵⁸
_____ Ginger²⁵⁹
_____ Glucosamine²⁶⁰
_____ Ji bu huan²⁶¹
_____ Milk thistle (Silymarin)²⁶²
_____ Senna²⁶³
_____ Shark Cartilage²⁶⁴
_____ Scurellaria (skullcap)²⁶⁵
_____ St. John's Wort²⁶⁶

- Other herbal 1 _____
Other herbal 2 _____
Other herbal 3 _____

Other Drugs

- _____ Heroin (injection)²⁶⁷
_____ MDMA/ "ecstasy"²⁶⁸
_____ Phencyclidine (Angel Dust)²⁶⁹
_____ Anabolic Steroids (injection)²⁷⁰
_____ Anabolic Steroids (by mouth)²⁷¹
_____ Glues or solvents²⁷²
_____ Cocaine (injection)²⁷³
_____ Cocaine (nasal)²⁷⁴
_____ Marijuana²⁶

- Other drug 1 _____
Other drug 2 _____
Other drug 3 _____

Section B. Activities and Pain

Please think about any pain you may have had in the past 4 weeks. Use a check (✓) to report whether you have had any of the following problems with work or other regular daily activities.

B1. Did you reduce the amount of time you spent on work, school or other activities?

- _____ Yes
- _____ No

B2. Did you accomplish less than you would like?

- _____ Yes
- _____ No

B3. Were you limited in the kind of work, school or other activities you performed?

- _____ Yes
- _____ No

B4. Did you have difficulty performing work or other activities, or did it take extra effort?

- _____ Yes
- _____ No

B5. How much pain in your joints did you have during the past 4 weeks?

- _____ None
- _____ Very mild
- _____ Mild
- _____ Moderate
- _____ Severe
- _____ Very severe

B6. How much pain of other types did you have during the past 4 weeks?

- _____ None
- _____ Very mild
- _____ Mild
- _____ Moderate
- _____ Severe
- _____ Very severe

B7. How much did pain interfere with your normal activities?

- _____ Not at all
- _____ A little bit
- _____ Moderately
- _____ Quite a bit
- _____ Extremely

Section C. Pain Medications

The following series of questions ask about your use of various types of pain medications. Please include both over-the-counter and prescriptions, brand names, store brand and generic versions. When reporting number of pills used, include capsules, caplets, and any other form.

Acetaminophen: Include any type of acetaminophen (Tylenol) and medications that combine acetaminophen with something else such as Tylenol #3, Darvocet, Percocet, Propacet, etc.

C1. During the past month, how often did you take acetaminophen for pain or discomfort?

- _____ Never
- _____ Less than once a week
- _____ At least once a week

For the next questions, record the amount of acetaminophen you took during the past three months. If you don't remember exactly, record your best guess.

C2. During the last 3 months, how much acetaminophen did you *usually* take in a week?

Pills per week # NONE

C3. During the last 3 months, what was the *maximum amount* of acetaminophen you took in any *one day*?

Pills per day # NONE

We've just looked back over the last 3 months. Now, we'd like you to think back over the past year up until 3 months ago.

C4. Between 3 and 12 months ago, how much acetaminophen did you *usually* take in a week?

Pills per week # NONE

C5. Between 3 and 12 months ago, what was the *maximum amount* of acetaminophen you took in any *one day*?

Pills per day # NONE

Non-Steroidal Anti-Inflammatory Drugs (NSAID) : Include any type of ibuprofen (Motrin, Nuprin, Advil) as well as Cox-2 inhibitors Vioxx, Celebrex, etc. If you are uncertain about whether a medication is in this category, please refer to the list provided by clinic staff.

C6. During the past two weeks, which Cox-2 inhibitors did you take for pain or discomfort?

- None → **Go to C7**
 Vioxx
 Celebrex
 Other (Specify) _____

6a. For how many months had you been using a Cox-2 inhibitor?

- Less than one month
 1-12 months
 More than 12 months

C7. During the past two weeks, did you take any other NSAIDs for pain or discomfort? *Please do not include the Cox-2 inhibitors listed at Question C6 above.*

- Yes
 No → **Go to C8**

C7a. For how many months had you been using any **other** NSAID?

- Less than one month
 1-12 months
 More than 12 months

For the next questions, record the amount of all NSAIDs you took during the past three months, including Cox-2 inhibitors such as Vioxx and Celebrex. If you don't remember exactly, record your best guess.

C8. During the last 3 months, what amount of NSAIDs did you **usually** take in a week?

Pills per week # NONE

C9. During the last 3 months, what was the **maximum amount** of NSAIDs you took in any **one day**?

Pills per day # NONE

We've just looked back over the last 3 months. Now, we'd like you to think back over the past year up until 3 months ago.

C10. Between 3 and 12 months ago, what amount of NSAIDs did you **usually** take in a week?

Pills per week # NONE

C11. Between 3 and 12 months ago, what was the **maximum amount** of NSAIDs you took in any **one day**?

Pills per day # NONE

Codeine and other Narcotics: *Include narcotic medications such as codeine, propoxyphene (Darvon), and morphine. Do not include medications with acetaminophen like Tylenol #3 and Darvocet.*

C12. During the past month, how often did you take codeine or other narcotics for pain or discomfort?

- _____ Never
- _____ Less than once a week
- _____ At least once a week

For the next questions, record the amount of narcotic medication you took during the past three months. If you don't remember exactly, record your best guess.

C13. During the last 3 months, how much codeine and other prescription narcotics did you **usually** take in a week?

Pills per week # Injections per week # NONE

C14. During the last 3 months, what was the **maximum amount** of codeine and other prescription narcotics you took in any **one day**?

Pills per day # Injections per day # NONE

We've just looked back over the last 3 months. Now, we'd like you to think back over the past year up until 3 months ago.

C15. Between 3 and 12 months ago, how much codeine and other prescription narcotics did you **usually** take in a week?

Pills per week # Injections per week # NONE

C16. Between 3 and 12 months ago, what was the **maximum amount** of codeine and other prescription narcotics you took in any **one day**?

Pills per day # Injections per day # NONE

Section D. Cigarette and Alcohol Use

D1. During the past year, have you smoked cigarettes regularly (at least 10 cigarettes per week)?

_____ Yes

_____ No

For the following questions, a 'drink' is defined as 12 oz. (360 ml) of beer, 4 oz. (120 ml) of wine, or 1 oz. (30 ml) of liquor. Please indicate your answers with a check (✓).

D2. During the past year, have you had a drink containing alcohol?

_____ Yes

_____ No → **Go to Section E**

For the next questions, record the number of drinks you during the past three months. Please give your best estimate. If you do not drink at all, mark 'none'.

D3. During the last 3 months, how many drinks did you **usually** have per week? (Give 1 answer only)

Per week # | | | |

LESS THAN 1 PER WEEK

NONE

D4. During the last 3 months, what was the **maximum** number of drinks had in any **one day**?

Maximum # in any one day | | | |

NONE

We've just looked back over the last 3 months. Now, we'd like you to think back over the past year up until 3 months ago.

D5. Between 3 and 12 months ago, how many drinks did you **usually** have per week? (Give 1 answer only)

Per week # | | | |

LESS THAN 1 PER WEEK

NONE

D6. Between 3 and 12 months ago, what was the **maximum number** of drinks you had in any **one day**?

Maximum # in any one day | | | |

NONE

Please answer the following questions while thinking of the last 12 months. For each question, circle the number the number that best represents your answer.

How often during the last year...	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
EXAMPLE:have you taken a vacation?	0	1	2	3	4
D7. ...have you found that you were unable to stop drinking once you had started?	0	1	2	3	4
D8. ...have you failed to do what was normally expected from you because of drinking?	0	1	2	3	4
D9. ...have you needed a drink first thing in the morning to get yourself going after a heavy drinking session?	0	1	2	3	4
D10.have you had a feeling of guilt or remorse after drinking?	0	1	2	3	4
D11. ...have you been unable to remember what happened the night before because you had been drinking?	0	1	2	3	4
D12. ...have you or someone else been injured as the result of your drinking?	0	1	2	3	4
D13. ...has a relative, friend, or a doctor or other health worker been concerned about your drinking or suggested you cut down?	0	1	2	3	4

Section E. Quality of Life

These last questions ask how you have been feeling over the past 2 weeks. Circle the number that corresponds to how often you felt that way. For example, circle 3 if you have been tired or fatigued some of the time during the past 2 weeks. Please circle only one number per line.

How much of the time during the past 2 weeks.....	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
EXAMPLE: have you been tired or fatigued?	6	5	4	3	2	1	0
E1. ...have you been troubled by a feeling of abdominal bloating?	6	5	4	3	2	1	0
E2. ...have you been tired or fatigued?	6	5	4	3	2	1	0
E3. ...have you experienced bodily pain?	6	5	4	3	2	1	0
E4. ...have you felt sleepy during the day?	6	5	4	3	2	1	0
E5. ...have you experienced abdominal pain?	6	5	4	3	2	1	0
E6. ...has shortness of breath been a problem for you in your daily activities?	6	5	4	3	2	1	0
E7. ...have you not been able to eat as much as you would like?	6	5	4	3	2	1	0
E8. ...have you been bothered by having decreased strength?	6	5	4	3	2	1	0

How much of the time during the past 2 weeks.....	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
E9. ...have you had trouble lifting or carrying heavy objects?	6	5	4	3	2	1	0
E10. ...have you felt anxious?	6	5	4	3	2	1	0
E11. ...have you felt a decreased level of energy?	6	5	4	3	2	1	0
E12. ...have you felt unhappy?	6	5	4	3	2	1	0
E13. ...have you felt drowsy?	6	5	4	3	2	1	0
E14. ...have you been bothered by a limitation of diet?	6	5	4	3	2	1	0
E15. ...have you been irritable?	6	5	4	3	2	1	0
E16. ...have you had difficulty sleeping at night?	6	5	4	3	2	1	0
E17. ...have you been troubled by a feeling of abdominal discomfort?	6	5	4	3	2	1	0
E18. ...have you been worried about the impact your hepatitis C virus infection has on your family?	6	5	4	3	2	1	0
E19. ...have you had mood swings?	6	5	4	3	2	1	0
E20. ...have you been unable to fall asleep at night?	6	5	4	3	2	1	0
E21. ...have you had muscle cramps?	6	5	4	3	2	1	0
E22. ...have you been worried that your symptoms will develop into major problems?	6	5	4	3	2	1	0
E23. ...have you had a dry mouth?	6	5	4	3	2	1	0
E24. ...have you felt depressed?	6	5	4	3	2	1	0
E25. ...have you been worried about your hepatitis C virus infection getting worse?	6	5	4	3	2	1	0
E26. ...have you had problems concentrating?	6	5	4	3	2	1	0
E27. ...have you been troubled by itching?	6	5	4	3	2	1	0
E28. ...have you been worried about never feeling any better?	6	5	4	3	2	1	0
E29. ...have you been concerned about the availability of a liver if you need a liver transplant?	6	5	4	3	2	1	0

When you are done with this form, return it to the study nurse. Thank you very much for taking part in this important research project. Your answers are of great value to this study.