ACTG Adherence Follow Up Questionnaire

Date _____ Self Interviewer Both

Patient ID _____ How Administered? ☐ 1 ☐ 2 ☐ 3

THIS PAGE IS TO BE COMPLETED BY THE PATIENT AND STUDY PERSONNEL TOGETHER.

A. You are currently taking the following drugs at the frequency and doses listed.

Study Drug Name/Dose	# Pills Each Time (Pills Each Dose)	# Times Per Day (Doses Per Day)

INSTRUCTIONS: Complete this worksheet with the patient.

The answers you give on this form will be used to plan ways to help other people who must take pills on a difficult schedule. Please do the best you can to answer all the questions. If you do not wish to answer a question, please draw a line through it. If you do not know how to answer a question, ask your study nurse to help. Thank you for helping in this important study.

PATIENT ONLY continue here.
The next section of the questionnaire asks about your HIV study medications that you took over the last four days.

Most people with HIV have many pills to take at different times during the day.
Many people find it hard to always remember their pills:

- Some people get busy and forget to carry their pills with them.
- Some people find it hard to take their pills according to all the instructions, such as "with meals," or "on an empty stomach," "every 8 hours," "with plenty of fluids."
- Some people decide to skip doses to avoid side effects or to just not be taking pills that day.

We need to understand how people with HIV are really doing with their pills. Please tell us what you are **actually** doing. Don't worry about telling us that you don't take all your pills. We need to know what is really happening, not what you think we "want to hear."

1. The next section of the questionnaire asks about the study medications that you may have missed taking over the last four days. Please complete the following table by filling in the boxes below.

IF YOU TOOK ONLY A PORTION OF A DOSE ON ONE OR MORE OF THESE DAYS, PLEASE REPORT THE DOSE(S) AS BEING MISSED.

Step 1 Names of your anti-HIV study drugs	HOW MANY DOSES DID YOU **MISS** . . .			
	Step 2 Yesterday	**Step 3** Day before yesterday (2 days ago)	**Step 4** 3 days ago	**Step 5** 4 days ago
	☐ doses	☐ doses	☐ doses	☐ doses
	☐ doses	☐ doses	☐ doses	☐ doses
	☐ doses	☐ doses	☐ doses	☐ doses
	☐ doses	☐ doses	☐ doses	☐ doses
	☐ doses	☐ doses	☐ doses	☐ doses
	☐ doses	☐ doses	☐ doses	☐ doses
	☐ doses	☐ doses	☐ doses	☐ doses

The following questions pertain to the study regimen on page 2.

If you took only a portion of a dose on one or more of these days, please report the dose(s) as being missed.

B. During the past 4 days, on how many days have you missed taking all your doses?

- ☐ None
- ☐ One day
- ☐ Two days
- ☐ Three days
- ☐ Four days

C. Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours." How closely did you follow your specific schedule over the last four days?

Never	Some Of The Time	About Half Of The Time	Most Of The Time	All Of The Time
☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

D. Do any of your anti-HIV medications have special instructions, such as "take with food" or "on an empty stomach" or "with plenty of fluids?"

☐ 1 Yes ☐ 2 No

If Yes, how often did you follow those special instructions over the last **four** days?

Never	Some Of The Time	About Half Of The Time	Most Of The Time	All Of The Time
☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

E. Some people find that they forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend—last Saturday or Sunday?

☐ 1 Yes ☐ 2 No

F. When was the last time you missed any of your medications? Check one.

☐ 5 Within the past **week**

☐ 4 1-2 **weeks** ago

☐ 3 2-4 **weeks** ago

☐ 2 1-3 **months** ago

☐ 1 More than 3 **months** ago

☐ 0 **Never** skip medications or **not applicable**

*If you **Never** skip medications, please go to **Section H** on page 5.*
Otherwise, please continue by answering the next set of questions.

G. People may miss taking their medications for various reasons. Here is a list of possible reasons why you may miss taking your medications. How often have you missed taking your medications because you: (Circle one response for each question.)

	Never	Rarely	Sometimes	Often
1. Were away from home?	0	1	2	3
2. Were busy with other things?	0	1	2	3
3. Simply forgot?	0	1	2	3
4. Had too many pills to take?	0	1	2	3
5. Wanted to avoid side effects?	0	1	2	3
6. Did not want others to notice you taking medication?	0	1	2	3
7. Had a change in daily routine?	0	1	2	3
8. Felt like the drug was toxic/harmful?	0	1	2	3
9. Fell asleep/slept through dose time?	0	1	2	3
10. Felt sick or ill?	0	1	2	3
11. Felt depressed/overwhelmed?	0	1	2	3
12. Had problems taking pills at specified times (with meals, on empty stomach, etc.)?	0	1	2	3
13. Ran out of pills?	0	1	2	3
14. Felt good?	0	1	2	3

H. The following questions ask about symptoms you might have had during the past four weeks. Please check the box that describes how much you have been bothered by each symptom.

		I DO NOT HAVE THIS SYMPTOM	I HAVE THIS SYMPTOM AND …			
			It doesn't bother me	It bothers me a little	It bothers me a lot	It bothers me terribly
1.	Fatigue or loss of energy?	0	1	2	3	4
2.	Fevers, chills or sweats?	0	1	2	3	4
3.	Feeling dizzy or lightheaded?	0	1	2	3	4
4.	Pain, numbness or tingling in the hands or feet?	0	1	2	3	4
5.	Trouble remembering?	0	1	2	3	4
6.	Nausea or vomiting?	0	1	2	3	4
7.	Diarrhea or loose bowel movements?	0	1	2	3	4
8.	Felt sad, down or depressed?	0	1	2	3	4
9.	Felt nervous or anxious	0	1	2	3	4
10.	Difficulty falling or staying asleep?	0	1	2	3	4
11.	Skin problems, such as rash, dryness or itching?	0	1	2	3	4
12.	Cough or trouble catching your breath?	0	1	2	3	4
13.	Headache?	0	1	2	3	4
14.	Loss of appetite or a change in the taste of food?	0	1	2	3	4

15.	Bloating, pain or gas in your stomach?	0	1	2	3	4
16.	Muscle aches or joint pain?	0	1	2	3	4
17.	Problems with having sex, such as loss of interest or lack of satisfaction?	0	1	2	3	4
18.	Changes in the way your body looks, such as fat deposits or weight gain?	0	1	2	3	4
19.	Problems with weight loss or wasting?	0	1	2	3	4
20.	Hair loss or changes in the way your hair looks?	0	1	2	3	4

Thank you very much for completing these questions.
The information that you provided will help with the development of better drug regimens for all patients with HIV.

PLEASE NOTE: Section "H" on this questionnaire was developed by Amy Justice and Linda Rabaneck. To cite this 20-item symptom index, please contact Dr. Amy Justice at Amy.Justice@med.va.gov.