

ADOLESCENT ADHERENCE QUESTIONNAIRE MODULE 2
GENERAL REASONS FOR NON-ADHERENCE
 NIAID PEDIATRIC AIDS CLINICAL TRIALS GROUP

Patient Number	<input type="text"/>	<input type="text"/>	<input type="text"/>	Date of Patient Visit	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Protocol Number	<input type="text"/>	<input type="text"/>	<input type="text"/>	Institution Code	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Form Week	<input type="text"/>	* Seq No.	<input type="text"/>	**Step No.	<input type="text"/>	Key Operator Code	<input type="text"/>	<input type="text"/>

* Enter a "1" if this is the first of this form for this date. Designate subsequent forms on the same date with a 2, 3, etc.
 **Enter the subject's current study step number. Enter '1' if the study does not have multiple steps.

This module captures the general reasons for non-adherence linked to each drug taken. In this step, the interviewer will collect information on reasons why the subject may be having difficulty taking each agent.

- This form should be completed for subjects ≥ 13 years of age. For subjects < 13 years of age, complete the PEDIATRIC ADHERENCE QUESTIONNAIRE MODULE 2 form (QL5001).
- If the subject has assumed sole responsibility for his/her own drug regimen, the subject should complete this form.
- If the primary caregiver is solely responsible for distributing the medications to the subject, the primary caregiver should complete this form.
- If the responsibility is shared, the subject and the caregiver should jointly complete this form.

QUESTIONS 1 - 5 ARE TO BE COMPLETED BY THE STUDY NURSE:

1. Was the questionnaire completed at this visit? (1-Yes, 2-No)
 If Yes, go to question 2.
 If No, complete 'a'.

a. Indicate the reason the questionnaire was not completed:
 1-Subject refused
 2-Primary caregiver refused
 3-Subject missed clinic visit
 4-There was not enough time
 5-Primary caregiver not available
 9-Other reason, specify

If Other, specify [30]: _____

2. Does the subject know his/her HIV status? (1-Yes, 2-No, 3-Information not available/not known)

3. Was the subject perinatally infected? (1-Yes, 2-No, 3-Information not available/not known)

4. Who is responsible for administering the medications?
 1-Primary caregiver solely responsible
 2-Subject solely responsible
 3-Subject and caregiver jointly
 4-Subject and other individual
 9-Other, specify

If "9-Other", specify [30]: _____

5. Who responded to the questions?.....
 1-Primary caregiver
 2-Caregiver and subject jointly
 3-Subject alone
 9-Other, specify

If "9-Other", specify [30]: _____



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INSTRUCTIONS FOR COMPLETION OF DRUG SPECIFIC TABLE:

- Enter the drug code name of each antiretroviral drug that the subject is receiving in the space provided at the top of each column. Refer to the bottom of this page for the list of most commonly used anti-HIV medications. Refer to Appendix 3 or the Drug Code Lookup Program at the DMC Web Site (<http://www.fstrf.org>) for any medications not listed.

Identification of Reasons for Non-Adherence:

READ the following paragraph to the subject or primary caregiver:

"Many people at one time or another have trouble with these medications. We would like to better understand the things that make giving medications hard for families. These are some of the reasons others have identified which have made it difficult to take [give] all of the HIV medicines."

Show and read the list of reasons to the subject or primary caregiver.

After the list is read, ask the following question for each drug (question 5 on pages 2 and 3):

"Over the last two weeks, have any of the following been problems for you with _____(drug name or characteristics)_____?"

If "Yes," enter the frequency code for each reason (a-r).

If "No," go to the next drug.

For data entry, use the tab key after the last entry on the page.

DRUG CODE REFERENCE

*Drug Codes and Names for Commonly Used Drugs.
Refer to Appendix 3 or the Drug Code Lookup Program at the
DMC Web Site (<http://www.fstrf.org>) for drugs not listed below.*

<u>Anti-HIV Drugs for Protocol</u>			
08180407	Abacavir/ABC/Ziagen/1592U89	08180043	Indinavir/IDV/Crixivan 10920013
08180025	Alovedine/CL-184824		Interleukin-2/IL-2
08181205	Amprenavir/APV/Agenerase/141W94/VX-479	08180026	Lamivudine/3TC/Epivir
08181214	Atazanavir/ATV/BMS-232632	08181208	Lopinavir/Ritonavir (LPV/RTV)/Kaletra ABT-378/r
08180018	Ateviridine mesylate U-87201E	08180048	Loviride/Lotrene
08180006	Azidouridine/AzdU/azido-2',3'-dideoxyuridine	08181204	Nelfinavir/NFV/Viracept
08180021	AZT/ZDV/Zidovudine/Retrovir	08180013	Nevirapine/NVP/Viramune
08180032	CD4/RST4	08181203	Ritonavir/RTV/Norvir
08180412	Combivir (3TC/ZDV)	08181209	Saquinavir soft gel/FTV/Fortovase
08180024	d4T/Stavudine/Zerit	08180030	Saquinavir (HGC)/SQV/Invirase/R031-8959
08180414	DAPD/Amdoxovir/trimeric	08188804	T-20/pentafuside/Enfuvirtide/ENF
08180020	ddC/Zalcitabine/HIVID	08182002	TDF/Tenofovir/Tenofovir disoproxil fumarate/Viread
08180007	ddI/Didanosine/Videx	08180418	Trizivir (3TC/ABC/ZDV)
08180031	DLV/delavirdine mesylate/Rescriptor		
08180804	Efavirenz/EFV/Sustiva/DMP266	99999998	Blinded Study Drug
08180411	Fluorouridine/935U83	99999999	Drug Code Pending
08180415	FTC/coviracil/emtricitabine		
08181218	GW433908		



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DRUG SPECIFIC ADHERENCE DIFFICULTIES:

Frequency Codes

Use these codes to indicate the frequency with which each listed reason for non-adherence occurs. This needs to be done for each antiretroviral drug the subject is taking.
 0-Never a problem
 1-Hardly ever a problem
 2-Frequent problem
 3-Almost always a problem

<i>Enter Drug Code and Name:</i>	<i>Drug Code [8]:</i>	<i>Drug Code [8]:</i>	<i>Drug Code [8]:</i>	<i>Drug Code [8]:</i>	<i>Drug Code [8]:</i>
	<i>Drug #1 Name [15]:</i>	<i>Drug #2 Name [15]:</i>	<i>Drug #3 Name [15]:</i>	<i>Drug #4 Name [15]:</i>	<i>Drug #5 Name [15]:</i>
6. Problem identified? (1-Yes, 2-No)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Reasons for Non-adherence:</i>					
a. Can't get drug at drug store	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Didn't get prescription refilled; ran out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Made me sick to my stomach; threw up; it tasted bad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Forgot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. It caused me to have other physical symptoms (e.g., rash, headache)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Got in the way of daily schedule (school, work); too busy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Couldn't deal with it; didn't feel like taking it; needed a break	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Change in living situation; moved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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	Drug #1	Drug #2	Drug #3	Drug #4	Drug #5
<i>Reasons for Non-adherence (cont'd):</i>					
i. Worried people would find out about HIV; didn't want friends asking questions; felt embarrassed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Got sick with another illness; wasn't feeling well (e.g., cold, flu, stomach bug)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Don't think I need it anymore; I can stay healthy without it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Family and/or friends don't help me remember; tell me I shouldn't take it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Nowhere to keep it at school or work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Don't understand why I have to take it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. I keep getting sick even when I <u>do</u> take it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Taking it reminds me of the HIV; just want to forget about the diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. I don't want to talk about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Other, specify Specify [30]:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Language:
English

