

Treatment Adherence Demonstration Project Baseline Client Interview

- **This questionnaire must be completed for all clients in the treatment adherence demonstration project; it should be completed at the time of their initial enrollment. Instructions are in bold throughout. Explanatory items, which should be read to the client, are in italics.**

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- **Questions (a) through (f) should be completed by the person conducting the interview.**

(a) Client ID: _____ (b) Date: ____/____/____
(13 digits) (mm) (dd) (yy)

(c) Adherence Program: _____ (d) Adherence Network Site: _____

(e) Reason for enrollment in the adherence program (**check all that apply**):

- client new to HAART
- client had previous adherence problems
- client has known risk factors for non-adherence
- client self-referred to program
- other (please specify) _____

(f) Person conducting the interview:

(i) Name _____

(ii) Interviewer's relationship to client: little or no contact
 occasional contact
 regular contact

I would first like to ask you about your HIV care and about things in your life that may affect your ability to get care.

1) What is your usual source of treatment for HIV/AIDS? (**check one**)

- No usual source of treatment (**skip to question 4**)
- Private doctor
- Community Health Center (not hospital-based)
- Hospital Clinic or Outpatient department
- HMO, Managed Care organization
- Drug Treatment Center

- Emergency room
- Other (please specify) _____

2) About how long does it normally take you to travel to appointments with your HIV primary care provider?

- Less than 30 minutes
- 30-59 minutes
- an hour or more
- Not applicable/no HIV primary care provider (**skip to question 4**)

3) How often is transportation a problem when you need to get to appointments with your HIV primary care provider?

- Rarely/never
- Some of the time
- Always or most of the time
- Not applicable/no HIV primary care provider

4) Do you regularly work outside the home (at least half time)?

- no
- yes

➤ Ask as an open ended question, then prompt for categories.

5) What kind of housing do you live in? (check one)

- Homeless (e.g., on the street, homeless shelter)
- Transitional (e.g., SRO, staying at other person's home/apartment)
- Institutional (e.g., Prison, Health Care Facility, Drug Rehab)
- Stable (e.g., home or apartment)
- Other _____

➤ Ask an open ended question, then prompt for categories (e.g. partner/spouse, parent(s), children, sister/brother, other relatives, friend, roommate, other residents, live alone)

6) Who do you live with? _____

7) How many children do you have that are under the age of 18? _____

a) How many children are you primarily responsible for? _____ (**if none, skip to question 8**)

b) Do any of these children have HIV or AIDS?

- no (**skip to 7-d**)
- yes

c) Do they get health care the same place as you?

- no
- yes

d) How often is child care a problem when you need to attend appointments or meetings?

- Seldom or never
- Some of the time
- Always or most of the time

8) Is there someone (like a friend or family member) who you can -- or will be able to -- regularly depend on to help you to take your HIV/AIDS medications?

- no
- yes

9) Are you currently taking antiretroviral therapy?

- no
- yes

10) How sure are you that the antiretroviral medication will help you fight the virus?

- not sure
- pretty sure
- very sure
- don't know

11) On average, how many pills do you actually take *each day*? This includes every type of pill you take, HIV and non-HIV, over-the-counter and by prescription. _____

a) How many times a day do you take pills? _____

(if client not on antiretroviral therapy, skip to question 22)

- **If the client is on antiretroviral therapy complete the table below. This chart is only for the client's antiretrovirals. Steps 1 through 3 should be generated interactively with the client, but must represent the client's understanding of his or her prescription and dosing. The suggested sequence for completing the table is to complete the full list of drugs in Step 1, then complete Steps 2 and 3 for each of the drugs, then Steps 4 through 6 for the first drug, Steps 4 through 6 for the second drug, etc.**

I'd next like to ask you some questions to help us understand your experience with the HIV antiretrovirals you are taking.

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 food" or "on an empty stomach," "every 8 hours", "with plenty of fluids."*
- *Some people decide to skip pills to avoid side effects or because they just don't want to take pills that day.*

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

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

Step 1 Names of antiretroviral drugs	Step 2 # Pills each time (pills each dose)	Step 3 # times per day (doses per day)	How many doses did you <u>miss</u> ... (write "dk" if the response is don't know)		
			Step 4 Yesterday	Step 5 Day before yesterday (2 days ago)	Step 6 3 days ago
12a)	13a)	14a)	15a)	16a)	17a)
12b)	13b)	14b)	15b)	16b)	17b)
12c)	13c)	14c)	15c)	16c)	17c)
12d)	13d)	14d)	15d)	16d)	17d)
12e)	13e)	14e)	15e)	16e)	17e)
12f)	13f)	14f)	15f)	16f)	17f)
12g)	13g)	14g)	15g)	16g)	17g)

The next questions ask about the antiretroviral regimen listed above.

➤ **Ask only if there were *no* missed doses in the table above. Otherwise skip to 19.**

18) When was the last time you skipped any of your medications?

- never skip medications
- more than 3 months ago
- 1-3 months ago
- 2-4 weeks ago
- 1-2 weeks ago
- Within the past week

19) Many anti-HIV medications have special instructions, like they need to be taken “every 8 hours” or they need to be taken “on an empty stomach,” or “with plenty of fluids.” How often in the last 3 days did you follow those special instructions?

- Never
- Some of the time
- About half of the time
- Most of the time
- All of the time

20) What’s the most common reason that you miss taking your medications? _____

Now, I’m going to read some reasons why people may miss taking their medications.

21) Please tell me how often any of these reasons apply to you. This is not just in the last 3 days, but generally speaking. (**check one response for each question**):

	Never	Rarely	Sometimes	Often
a) Taking pills didn’t fit in with your daily routine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Simply forgot?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Too hard to take so many pills according to a schedule?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Wanted to avoid side effects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Felt like the drug was toxic/harmful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Did not want others to notice you taking medication?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Fell asleep/slept through dose time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Felt sick or ill?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Rarely	Sometimes	Often
i) Felt depressed/overwhelmed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Ran out of pills?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Felt good?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Didn't understand regimen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) You knew what was best for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Didn't fit with meals/didn't have water?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) Didn't feel like taking pills?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) Were drunk or high?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Other, (specify)_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Now I would like to ask you some questions about your understanding of HIV and HIV medications. Please answer "true" or "false." (Do not give client the option of "don't know," but if the client clearly does not know, check the "don't know" box)

22) It's OK to stop taking HIV medicines once you feel better.

- true false don't know

23) You should take your medicines exactly as prescribed, or you may never be able to use those medicines again.

- true false don't know

24) A CD4 or t-cell count is one measure of what HIV has done to the immune system.

- true false don't know

25) HIV is cured when the viral load test comes back undetectable.

- true false don't know

26) To fight HIV, it is better to take more than one medicine, rather than one medicine by itself.

- true false don't know

Next, we have some questions on drug use. I first want to remind you that your answers are confidential.

We are asking these questions because we want to understand how using drugs might affect the way people take their medications.

➤ **For “when was the last time” below, do not read the categories; check the one that best reflects the client’s answer.**

- 27) a) Have you ever used cocaine or crack? **(if no skip to 27 b)** no yes
 i) If yes, when was the last time?
 longer than 3 months ago within the last 3 months within the last 3 days
- b) Have you ever used heroin? **(if no skip to 27 c)** no yes
 i) If yes, when was the last time?
 longer than 3 months ago within the last 3 months within the last 3 days
- c) Have you ever used amphetamines (speed)? **(if no skip to 27 d)** no yes
 i) If yes, when was the last time?
 longer than 3 months ago within the last 3 months within the last 3 days
- d) Have you ever used marijuana? **(if no skip to 28)** no yes
 i) If yes, when was the last time?
 longer than 3 months ago within the last 3 months within the last 3 days
- 28) Has there been a time in your life when you regularly had more than 3 drinks (including beer) a day? **(if no skip to 29)** no yes
 (a) Has there been a time within the last 3 months when you regularly had that many drinks? **(if no skip to 29)** no yes
 (b) Have you had that many drinks on any day in the last 3 days? no yes
- 29) Are you currently receiving any of the following support services?
- (a) home health care no yes
- (b) peer education/support no yes
- (c) buddy services no yes
- (d) personal care (help with dressing, bathing, etc.) no yes
- (e) homemaker service (help with housework, shopping, etc.) no yes
- (f) mental health counseling no yes
- (g) HIV adult day care no yes
- (h) harm reduction no yes

- (i) needle exchange no yes
- (j) case management services no yes
- (k) directly observed therapy (DOT) for TB no yes
- (l) other (specify) _____ no yes
- 30) Are you currently participating in any NA, AA, or other 12-step programs? no yes
- 31) Have you ever been in drug treatment? **(if no skip to 32)** no yes
- (a) Are you currently in a residential drug treatment program? no yes
- (b) Are you currently in a methadone program? no yes
- (c) Are you currently in an outpatient drug treatment program (other than NA or AA)? no yes
- 32) Have you ever been in a detox program? **(if no skip to 33)** no yes
- (a) If yes, when was the most recent time?
- within the last 3 months?
 - longer than 3 months, but within the last year
 - longer than a year
- 33) In the past month, how often have you felt:
- (a) that you were unable to control the important things in your life **(have client answer according to whatever is most important to him or her)**
- never or rarely sometimes often mostly or always
- (b) confident in your ability to handle your personal problems?
- never or rarely sometimes often mostly or always
- (c) that things were going your way?
- never or rarely sometimes often mostly or always
- (d) difficulties were piling up so high that you could not handle them?
- never or rarely sometimes often mostly or always

Finally, we'd like to ask a few background questions about you. We ask them to find out what kinds of

people are enrolled in the adherence support program.

34) What is your birthdate: ____/____/_____
(MM) (DD) (YYYY)

35) How would you define your race and ethnicity (**ask an open-ended question, check all mentioned**):

- White
- African American/Black
- Hispanic/Latino
- Caribbean/West Indian
- Asian/Pacific Islander
- Native American/Alaskan Native/Aleutian Islander
- Other (please specify)_____

36) What country(ies) does your family come from? _____

37) What is the highest level of education that you completed?

- 8th grade or less
- some high school (grades 9-11)
- high school graduate or GED
- some college or technical school (1-3 years)
- college graduate
- advanced degree

➤ **Questions (g) - (l) should be completed by the person conducting the interview.**

(g) Primary language of the client (check one):

- English (**skip to question i**)
- Spanish
- Other (please specify) _____

(h) If primary language is not English, does the client speak English?

- Adequate English language skills
- Limited English language skills
- Does not speak English

(i) Was this interview conducted in a language other than English?

- yes
- no

(j) Would you say that the respondent's answers were generally reliable?

- yes
- no

(k) Was the respondent's report of his or her antiretroviral regimen (in questions 12-14, above) correct?

- yes
- no
- don't know
- not applicable

(l) Optional comments (**e.g. reliability of responses to particular questions; any other important information that was not captured**):