

Attachment 2c

Proxy Questionnaire for Medical Monitoring Project (MMP)

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VERSION 1

Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC, Project Clearance Officer, 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0011). Do not send the completed form to this address.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

Centers for Disease Control and Prevention

Atlanta, GA 30333



2007 MMP PROXY QUESTIONNAIRE

Participant ID: _____
_____ Site ID Facility ID Respondent
ID

Interviewer ID: _____

Population Definition Period (PDP) START date: (_____/_____/_____
_____)
(M M / D D / Y Y Y Y)

Population Definition Period (PDP) END date: (_____/_____/_____
_____)
(M M / D D / Y Y Y Y)

Interview date: (_____/_____/_____
(M M / D D / Y Y Y Y))

Interview language: 1 English 2 Spanish
 3 Other (*Specify*_____)

Time questionnaire began: ____:____ AM PM
Hour Minute

Note to Reviewer: The QDS version of this interview will be programmed to determine the age of the participant based on the Patient Definition Period Start Date. As described in the protocol, all participants must have been 18 years of age or older on the date written in this area.

SAY: “I’d like to thank you for taking part in this survey. Remember that all the information you give me will be confidential. **Neither** your name **nor** the patient’s name will be recorded anywhere on this paper. To begin, I would like to ask you about **[INSERT PATIENT’S NAME]** previous participation in the Medical Monitoring Project (MMP).

Q1. To your knowledge, has **[INSERT PATIENT’S NAME]** ever participated in the MMP interview? If you or anyone else participated in the MMP interview on **his/her** behalf, please include this, as well.

- No..... 00 
- Yes..... 01
- Refused to answer 07
- Don’t know 09 

Q1a. What month and year did **he/she** participate in the MMP interview?

(M M / Y Y Y Y) —

[77 = Refused, 99 = Don’t know]

Q1b. Where was **he/she** interviewed?

_____ (City)


_____ (State)

[77 = Refused, 99 = Don’t know]

Interview instructions: If the patient was previously interviewed in a month during which 2006 data collection cycle interviews were conducted, go to Say Box before Q2. Otherwise, skip to Q2.

SAY: “We are only interviewing people this year who haven’t already been interviewed during 2006 (or 2007). Thank you very much for your time.” **[DISCONTINUE INTERVIEW AND GO TO INTERVIEW COMPLETION MODULE.]**

Q2. Is **[INSERT PATIENT’S NAME]** living or deceased?

- Living..... 01 
- Deceased..... 02

Q2a. What was the date of **his/her** death?

(M M / D D / Y Y Y Y) —

[77 = Refused, 99 = Don’t know]

Q2b. What is your relationship to **him/her**? [**CHECK ONLY ONE RESPONSE.**] [**DON'T READ CHOICES.**]

- Spouse or partner..... 01
- Girlfriend or boyfriend..... 02
- Friend..... 03
- Neighbor..... 04
- Parent..... 05
- Sibling..... 06
- Child..... 07
- Grandparent..... 08
- Grandchild..... 09
- Aunt/Uncle..... 10
- Niece/Nephew..... 11
- Cousin..... 12
- In-law 13
- Care giver 14
- Other 15
(Specify: _____)
- Refused to answer..... 77
- Don't know..... 99

Q3. What is **your** date of birth?

(M / M / D / D / Y / Y - Y - Y) — —

Interviewer instructions: If person serving as a proxy is less than 18 years of age, go to Say Box before Q3a; otherwise, skip to Q3a.

SAY: “We are only interviewing people who are 18 years or older. Thank you very much for your time.” [DISCONTINUE INTERVIEW AND GO TO INTERVIEW COMPLETION MODULE.]

Q3a. What is **his/her** date of birth?

(M / M / D / D / Y / Y - Y - Y) — —

[77 = Refused, 99 = Don't know]

Interviewer instructions: If respondent was less than 18 years of age on PDP start date, go to Say Box before Q4; otherwise, skip to Q4.

SAY: “We are only collecting information about people who were 18 years or older on _____/ _____ [BEGINNING OF THE PDP]. Thank you very much for your time.” [DISCONTINUE INTERVIEW AND GO TO INTERVIEW COMPLETION MODULE.]

Q4. What was **his/her** sex at birth? **[CHECK ONLY ONE RESPONSE.] [READ CHOICES EXCEPT "Intersex/ambiguous".]**

- Male..... 01
- Female..... 02
- Intersex/ambiguous..... 03
- Refused to answer..... 07
- Don't know..... 09

Q4a. Does (did) **he/she** consider **himself/herself** to be male, female, or transgender? **[CHECK ONLY ONE RESPONSE.]**

- Male..... 01
- Female..... 02
- Transgender..... 03
- Refused to answer..... 07
- Don't know..... 09

Q5. What is the highest level of education **he/she** completed? **[CHECK ONLY ONE RESPONSE.][DON'T READ CHOICES.]**

- Never Attended School..... 01
- Grades 1 through 8 02
- Grades 9 through 11..... 03
- Grade 12 or GED..... 04
- Some College, Associate's Degree,
or Technical Degree.. 05
- Bachelor's Degree..... 06
- Any post-graduate studies 07
- Refused to answer..... 77
- Don't know..... 99

Q6. Does (Did) **he/she** consider **himself/herself** to be Hispanic or Latino/a?

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Skip to Q7 →

} **Skip to Q7**

Q6a. What best describes **his/her** Hispanic ancestry? **[CHECK ALL THAT APPLY.] [DON'T READ CHOICES.]**

- Mexican..... 01
- Puerto Rican..... 02
- Cuban..... 03
- Dominican..... 04

- Other (*Specify:* _____)..... 05
- Refused to answer..... 07
- Don't know..... 09

Q7. Which racial group or groups does (did) **he/she** consider **himself/herself** to be in? You may choose more than one option. **[CHECK ALL THAT APPLY.][READ CHOICES.]**

- Asian..... 01
- Black or African American..... 02
- American Indian or Alaska Native..... 03
- Native Hawaiian or other Pacific Islander..... 04
- White..... 05
- Other (*Specify:* _____)..... 06
- Refused to answer..... 07

Q8. In the **past 12 months**, has (had) **he/she** been homeless at any time? By homeless, I mean **he/she** was living on the street, in a shelter, a Single Room Occupancy (SRO) hotel, temporarily staying with friends/family, or living in a car.

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Q9. In the **past 12 months**, has (had) **he/she** had any kind of health insurance or coverage? I am not referring to coverage for medicines only.

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Skip to Q10 →

} **Skip to Q10**

Q9a. Was there a time in the **past 12 months** that **he/she didn't** have any insurance coverage?

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Q10. What are the main ways **his/her** prescription medicines for HIV and related illnesses were paid for in the **past 12 months**? **[CHECK ALL THAT APPLY.] [DON'T READ CHOICES.]**

- He/she** wasn't taking any prescription medicines for HIV or related illnesses..... 01
- Private health care coverage..... 02
- He/she** got **his/her** HIV medicines at a public clinic..... 03
- He/she** paid for my HIV medicines **himself/herself** ("out of pocket")..... 04

- AIDS Drug Assistance Program (ADAP)..... 05
- He/she** participated in a clinical research trial or drug study that provided **his/her** medicines..... 06
- An AIDS service organization provided **him/her** medicines..... 07

- Medicaid/Medicare..... 08
- Other (*Specify:* _____).... 09
- Refused to answer..... 77
- Don't know..... 99

- Q11. In the **past 12 months**, has (had) **he/she** received any form of public assistance or welfare, including Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI)?
- No, and **he/she** hasn't applied for any 00
 - No, **he/she** applied, but hasn't received any..... 01
 - Yes, **he/she** received..... 02
 - Refused to answer..... 07
 - Don't know..... 09

SAY: "Now I'm going to ask you some questions about getting tested for HIV and the care that **he/she** is (was) receiving for HIV."

Q12. When did **he/she first** test positive for HIV?

____/____/____
(M M / Y Y Y Y)

[77 = Refused to answer, 99 = Don't know]

Interviewer instructions: If date of first HIV positive test is after the PDP end date, confirm the date in Q12. If the date is correct, go to the Say Box before Q13; otherwise, go to Q13

SAY: "We are only interviewing people who tested positive for HIV before ____/____ [end of the PDP]. Thank you very much for your time." [DISCONTINUE INTERVIEW AND GO TO INTERVIEW COMPLETION MODULE.]

Q13. When did **he/she first** go to a health care provider for HIV-related care after learning **he/she** had HIV?

____/____/____
(M M / Y Y Y Y)

[77 = Refused, 99 = Don't know]

If date of first HIV-related care is after the PDP end date, confirm the date in Q13. If the date is correct, go to the Say Box below; otherwise, skip to Q14.

Say: “We are only interviewing people whose first HIV-related care was before ____/____ [END OF THE PDP]. Thank you very much for your time.” [DISCONTINUE INTERVIEW AND GO TO INTERVIEW COMPLETION MODULE.]

Q14. When did **he/she** last go to a health care provider for HIV care?

____/____
 (M M / Y Y Y Y) [77 = Refused to answer, 99 = Don't know]

SAY: “Now I’m going to ask you some questions about places where **he/she** gets (got) medical care for HIV. If you don’t know everything, that’s okay. Tell me what you remember.”

Q15. In the **past 12 months**, is (was) there one place in particular, like a doctor’s office or clinic, where **he/she** usually goes (went) for most of **his/her** HIV care, like CD4 tests, viral load tests or HIV medicines?

- No..... 00
- Yes..... 01 → **Skip to Q15b**
- Refused to answer..... 07
- Don't know..... 09
- } **Skip to Q16**

Q15a. What are (were) the reasons **he/she** doesn't (didn't) have a usual source of care for treatment of HIV? [CHECK ALL THAT APPLY.] [DON'T READ CHOICES.]

- Couldn't afford a usual source of care..... 01
- Didn't know where to find regular HIV care..... 02
- Couldn't get a regular appointment anywhere..... 03
- No HIV doctors in **his/her** area..... 04
- Didn't think it was necessary..... 05
- Thought it was necessary, but never tried to get one 06
- Didn't know where to find a regular doctor who speaks the same language as **him/her**..... 07
- Have just recently been diagnosed 08
- Did not feel the need to seek treatment for HIV 09
- Other (*Specify:* _____)..... 10
- Refused to answer..... 77
- Don't know..... 99

Interviewer instructions: Skip to Q16

Q15b. What is the name of the place? Remember, this information will be kept private.

Name: _____

Interviewer instructions: After recording response, go to paper Facility Visits Log and enter location information and additional information for this place. After entering this information, continue with the next question.

Note: Responses to this question and other similar facility contact questions are not collected for analysis, but only for obtaining sufficient contact information to locate respondent's chart for medical record abstraction.

Note: QDS coding will allow for all possible facilities that participant describes. This rule applies to all other questions like this.

Q15c. Did **he/she** get HIV medical care at _____ **[THIS PLACE]** between ____/____ **[BEGINNING OF THE PDP]** and ____/____ **[END OF THE PDP]**?

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Q16. In the **past 12 months**, has (had) **he/she** been to any other doctor's office or clinic for **his/her** HIV care? If **he/she** was in jail or prison during the last 12 months, please include those providers as well.

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

skip to Q17 →

} **Skip to Q17**

Q16a. What is the name of the place?

Name: _____

Interviewer instructions: After recording response, go to paper Facility Visits Log and enter location information and additional information for this place. After entering this information, continue with the next question.

Q16b. Did **he/she** get HIV medical care at _____ **[THIS PLACE]** between ____/____ **[BEGINNING OF THE PDP]** and ____/____ **[END OF THE PDP]**?

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Q17. During the **past 12 months**, how many times did **he/she** go to an emergency room for HIV care? (Please don't include visits related to injuries such as accidents or other types of injuries).

[77=Refused to answer, 99=Don't know]

Q18. During the **past 12 months**, how many times did **he/she** go to an urgent care center for HIV care? (Please don't include visits related to injuries such as accidents or other types of injuries).

[77=Refused to answer, 99=Don't know]

Q19. During the **past 12 months**, how many times was **he/she** admitted to a hospital because of an HIV-related illness? (Please don't include visits that were made only to the Emergency Room.)

[77=Refused to answer, 99=Don't know]

If Q19 is "0", skip to Say Box before Q20.

Q19a. What is the name of the hospital where **he/she** was admitted?

Name: _____

Interviewer instructions: After recording response, go to paper Facility Visits Log and enter location information and additional information for this place. After entering this information, continue with the next question.

Q19b. Was **he/she** hospitalized at _____ **[THIS PLACE]** between ____/____ **[BEGINNING OF THE PDP]** and ____/____ **[END OF THE PDP]**?

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

SAY: "Now I'm going to ask some questions about the medicines that **he/she** was taking. To begin, I'll ask about medicines **his/her** doctor prescribed to treat **his/her** HIV."

Q20. Has (had) **he/she ever** taken any antiretroviral medicines to treat **his/her** HIV? These medicines are also known as ART, HAART, or the AIDS cocktail.

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

Skip → Q21
Skip to Say Box before Q22

Q20a. What are the reasons **he/she** has (had) never taken any antiretroviral medicines? **[CHECK ALL THAT APPLY.] [DON'T READ CHOICES.]**

- Doctor advised to delay treatment..... 01
- Recently into medical care/haven't had time..... 02
- CD4 count and/or viral load are good..... 03
- Feel good, don't need them..... 04
- Worried about side effects 05
- Drinking or using drugs..... 06
- Didn't want to think about being HIV positive..... 07
- No money..... 08
- No insurance..... 09
- Worried about ability to adhere/often forget..... 10
- Living on the street..... 11

- Taking alternative/complimentary medicines..... 12
- Other 13
(Specify: _____)
- Refused to answer 77
- Don't know..... 99

Interviewer instructions: Skip to Say Box before Q22

Q21. Has (had) **he/she** taken antiretroviral medicines in the **past 12 months**?

- No..... 00
- Yes..... 01
- Refused to answer..... 07
- Don't know..... 09

SAY: “Now I am going to ask you some questions about **his/her** need for services related to HIV.”

In the **past 12 months**, has (had) **he/she** needed any of these services: **[SHOW RESPONSE CARD F.]**
[READ CHOICES.]

Interviewer instructions: If response to Q22a is “No”, 77 or 99, skip to Q23a; otherwise, go to Q22b. If response to Q22b is “Yes”, 77 or 99, skip to Q23a; otherwise, go to Q22c. Follow the same pattern for Q22-Q35.

	[Needed this service in the past 12 months?]	If “Yes” in Q22a-Q35a, ask: Has (had) he/she been able to get this service in the past 12 months?	If “No” in Q22b-Q35b, ask: What was the main reason he/she hasn’t (had not) been able to get this service?
	CODE: No = 00, Yes = 01, Refused to answer= 77, Don’t know = 99	CODE: No = 00, Yes = 01, Refused to answer= 77, Don’t know = 99	See code list below for responses [ENTER ONLY ONE RESPONSE.] [DON’T READ CHOICES.]
Q22. HIV case management services	a. [_____]	b. [_____]	c. [_____]
Q23. Mental health counseling	a. [_____]	b. [_____]	c. [_____]
Q24. Social services, such as insurance assistance or financial counseling	a. [_____]	b. [_____]	c. [_____]

If “Yes” in Q22a-

		[Needed this service in the past 12 months?]	Q35a, ask: Has (had) he/she been able to get this service in the past 12 months?	If "No" in Q22b- Q35b, ask: What was the main reason he/she hasn't (had not) been able to get this service?
		CODE: No = 00, Yes = 01, Refused to answer= 77, Don't know = 99	CODE: No = 00, Yes = 01, Refused to answer= 77, Don't know = 99	See code list below for responses [ENTER ONLY ONE RESPONSE.] [DON'T READ CHOICES.]
Q25.	Assistance in finding a doctor for ongoing medical services		a. [____] b. [____] c. [____]	
Q26.	Assistance in finding dental services		a. [____] b. [____] c. [____]	
Q27.	Adherence support services		a. [____] b. [____] c. [____]	
Q28.	Home health services, such as nursing care or assistance	home	a. [____] b. [____] c. [____]	
Q29.	Chore or homemaker services or volunteer)	(paid	a. [____] b. [____] c. [____]	
Q30.	Assistance in finding shelter or housing		a. [____] b. [____] c. [____]	
Q31.	Assistance with finding meals or	food	a. [____] b. [____] c. [____]	
Q32.	Transportation assistance		a. [____] b. [____] c. [____]	
Q33.	Childcare services		a. [____] b. [____] c. [____]	
Q34.	Education or information on HIV risk reduction	risk	a. [____] b. [____] c. [____]	
Q35.	Other (Specify: _____)		a. [____] b. [____] c. [____]	

Interviewer instructions: For Q22c-Q35c: [ENTER ONLY ONE RESPONSE.][DON'T READ CHOICES.]

- 01. Didn't know where to go or who to call
- 02. Didn't complete application process
- 03. The system is too confusing
- 04. The waiting list is too long
- 05. It's not available in my area
- 06. They charge too much

- 07. Didn't have the money to pay
- 08. Transportation problems
- 09. Language barrier
- 10. Not eligible / Denied services
- 11. Too sick to get out
- 12. Other (**Specify**_____)
- 77. Refused
- 99. Don't know

Time questionnaire ended: ____ ____ : ____ ____ **AM** **PM**
Hour Minute

Interview Completion

END OF INTERVIEW

SAY: "Thank you again for taking part in this survey. Please remember that all the information you have given me will be kept private."

Interviewer instructions:

Offer assistance with information and resources, according to local protocol.

If interview was discontinued due to prior interview during the current calendar year OR respondent age < 18, don't pay the respondent.

If interview was discontinued due to first HIV positive test after the PDP, OR interview was partially/fully completed, pay the respondent and have him/her sign the receipt.

Interviewer: Please enter the following items after completion of the interview.

PAYMENT VERIFICATION

- C1. Payment made:
- | | | |
|-----------|----|--------------|
| No..... | 00 | ➔ Skip to C2 |
| Yes | 01 | |
- C1a. Why was payment not made?
- | | | |
|----------------------------------|----|--------------|
| Participant refused payment..... | 01 | ➔ Skip to C3 |
| Other..... | 02 | ➔ Skip to C3 |
- (Specify:) _____
- C2 Receipt signed (or initialed):
- | | | |
|----------|----|--------------|
| No..... | 00 | |
| Yes..... | 01 | ➔ Skip to C3 |
- C2a. Why was receipt not signed?
- | | | |
|----------------------------------|----|--|
| Participant refused to sign..... | 01 | |
| Other..... | 02 | |
- (Specify:) _____
- C3. Reason *MMP Proxy Questionnaire* was administered:
- | | | |
|------------------------------|----|--|
| Participant is ill..... | 01 | |
| Participant is deceased..... | 02 | |

