

**Attachment 2a. Standard Structured  
Questionnaire For Never In Care Project**

## Never in Care Project (NIC) 2007 Standard Questionnaire

### VERSION 1.3

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Public reporting burden of this collection of information is estimated to average 30 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-XXXX). Do not send the completed form to this address.

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#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

Centers for Disease Control and Prevention  
Atlanta, GA 30333



**PRELIMINARY INFORMATION**

*Interviewer instructions: Enter Preliminary Information prior to the interview.*

P1. *Never In Care ID Number:* \_\_\_\_\_

*Inconsistency check: P1 cannot be greater than 22 digits.*

P2. *HIV/AIDS Reporting System (HARS) Mode of Exposure:* \_\_\_\_

*Inconsistency check: P2 cannot be less than 0 or greater than 9.*

P3. *Interviewer ID:* \_\_\_\_

*Inconsistency check: P3 cannot be less than 1 or greater than 20.*

P4. *Date first positive test reported:* \_\_\_\_ / \_\_\_\_ / \_\_\_\_ - \_\_\_\_ - \_\_\_\_  
M M D D Y Y Y Y

*Inconsistency check: P4 cannot be earlier than 07/01/2006 and cannot be later than current date.*

P5. *Interview location: [CHOOSE ONE.]*

- 1 *Indiana*
- 2 *New Jersey*
- 3 *New York City*
- 4 *Philadelphia*
- 5 *Washington*

P6. *Interview date:* \_\_\_\_ / \_\_\_\_ / \_\_\_\_ - \_\_\_\_ - \_\_\_\_  
M M D D Y Y Y Y

*Inconsistency check: P6 cannot be earlier than 10/01/2007 or later than current date.*

P7. *Time questionnaire began:*  
\_\_\_\_ : \_\_\_\_ AM PM

**ELIGIBILITY**

**SAY:** "I'd like to thank you for taking part in this interview. Remember that all the information you give me will be private and your name will **not** be recorded anywhere on this form (computer).

E1. What is your date of birth?

\_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_  
M M D D Y Y Y Y

[Month: 77 = Refused to answer, 88= Don't know; Day: 77 = Refused to answer, 88= Don't know  
Year: 7777 = Refused to answer, 8888 = Don't know]

**Inconsistency check:** E1 cannot be earlier than 01/01/1900.

**Interviewer instructions:** If "Refused to answer" or "Don't know," skip to Say box before E2.

E1a. So, you are \_\_\_\_ [AGE] years old. Is that correct?

- 0 No.....**SAY:** "Please tell me your date of birth again." [RETURN TO E1.]
- 1 Yes
- 7 Refused to answer.....Skip to Say box before E2
- 8 Don't know.....Skip to Say box before E2

**Interviewer instructions:** If respondent is less than 18 years old, go to Say box before E2; otherwise skip to E2

**SAY BOX:** "We are only interviewing people who are 18 years or older. Thank you very much for your time."  
[DISCONTINUE INTERVIEW AND SKIP TO INTERVIEW COMPLETION.]

E2. Do you live in \_\_\_\_\_ [USE INTERVIEW LOCATION FROM P5.]?

- 0 No
- 1 Yes.....Skip to E2b
- 7 Refused to answer.....Skip to Say box before E3
- 8 Don't know.....Skip to Say box before E3

E2a. In which city and state do you live?

\_\_\_\_\_ / \_\_\_\_\_  
(City) (State)

- 7 Refused to answer
- 8 Don't know

**Interviewer instructions:** Skip to Say box before E3.

E2b. What is your zip code?

\_\_\_\_\_

- 777777 Refused to answer
- 888888 Don't know

**Interviewer note:** If respondent does not have a permanent residence, use the zip code where he or she is

currently residing.

**Inconsistency check:** E2b cannot be greater than 5 digits.

**Interviewer instructions:** Skip to E3.

**SAY:** “At this time we are only interviewing people who live in \_\_\_\_ [USE INTERVIEW LOCATION FROM P5]. Thank you very much for your time.” [DISCONTINUE INTERVIEW AND SKIP TO INTERVIEW COMPLETION SECTION.]

E3. What month and year did you **first** test positive for the human immunodeficiency virus ( HIV)? When I say “first test positive,” I mean the very first time you ever had a test result that was positive.

\_\_ / \_\_  
M M Y Y Y Y

[Month: 77 = Refused to answer, 88= Don’t know;  
Year: 7777 = Refused to answer, 8888 = Don’t know]

**Interviewer note:** If respondent has difficulty remembering the date, suggest key dates and seasons to narrow the time period (i.e. “Was it in the winter or summer?”)

**Inconsistency check:** E3 cannot be earlier than 03/1985 and cannot be later than current date.

**SAY:** “The next question is about medical care you may have received for HIV. When I say ‘HIV medical care’, I mean physical exams and lab tests such as HIV viral load and CD4 testing that can tell your doctor how fast the virus is multiplying and how your body is fighting the virus.”

E4. **Since you tested positive for HIV**, have you seen a doctor, nurse, or other health care worker for HIV medical care?

- 0 No.....Skip to Say box before D1
- 1 Yes
- 7 Refused to answer.....Skip to Say box after E7a
- 8 Don’t know..... Skip to Say box after E7a

E5. What month and year did you **first** see a doctor, nurse, or other health care worker for HIV medical care?

\_\_ / \_\_  
M M Y Y Y Y

[Month: 77 = Refused to answer, 88= Don’t know;  
Year: 7777 = Refused to answer, 8888 = Don’t know]

**Inconsistency check:** Confirm response if E5 is earlier than 03/1985. E5 cannot be later than current date.

**Interviewer instructions:** If E3 (date first tested positive) is later than E5, confirm dates in both E3 and E5. If E3 and E5 are the same date, go to E5a; otherwise, skip to E6.

E5a. You said that you got HIV medical care on the same day that you tested positive for HIV. Did you get any HIV medical care after [INSERT DATE FROM E5]?

- 0 No.....Skip to Say box before D1
- 1 Yes
- 7 Refused to answer
- 8 Don’t know

E6. When you **first** went for HIV medical care, in what city and state did you get care? Please tell me the country if you received care outside the U.S.

\_\_\_\_\_/\_\_\_\_\_  
(City) (State)

\_\_\_\_\_  
(Country)

- 7 Refused to answer
- 8 Don't know

**Interviewer instructions: If respondent identifies a U.S. city and state, skip to E7.**

E6a. **Since you tested positive for HIV**, have you seen a doctor, nurse, or other health care worker for HIV medical care in the U.S.?

- 0 No.....**Skip to Say box before D1**
- 1 Yes
- 7 Refused to answer.....**Skip to Say box after E7a**
- 8 Don't know..... **Skip to Say box after E7a**

E6b. When you **first** went for HIV medical care in the U.S., what city and state did you get care in?

\_\_\_\_\_/\_\_\_\_\_  
(City) (State)

- 7 Refused to answer
- 8 Don't know

E7. **Since you tested positive for HIV**, have you had a CD4 test or viral load test?

- 0 No
- 1 Yes
- 7 Refused to answer
- 8 Don't know

E7a. **Since you tested positive for HIV**, have you participated in an HIV clinical trial? When I say "HIV clinical trial," I mean a study that tests how well new medications or other HIV treatments work in people.

- 0 No
- 1 Yes
- 7 Refused to answer
- 8 Don't know

**SAY:** "At this time, we are only interviewing people who have **never** received medical care for their HIV infection in the U.S. Thank you very much for your time." **[OFFER INFORMATION AND RESOURCES ACCORDING TO PROTOCOL. DISCONTINUE INTERVIEW AND SKIP TO INTERVIEW COMPLETION SECTION.]**

## **DEMOGRAPHICS**

**SAY:** Now I would like to ask you some questions about your background. The answers to some questions may seem obvious to you, but I need to ask you all of the questions.”

D1. In what country or territory were you born? **[DON'T READ CHOICES. CHOOSE ONE.]**

- 1 United States.....*Skip to D2*
- 2 Puerto Rico.....*Skip to D2*
- 3 Mexico
- 4 Other (*Specify:* \_\_\_\_\_)
- 7 Refused to Answer.....*Skip to D2*
- 8 Don't Know.....*Skip to D2*

D1a. How many years have you been living in the United States?

— — — (years)

- 777 Refused to answer
- 888 Don't know

**Interviewer instructions: If less than one year, enter "0."**

**Inconsistency check: D1a cannot be less than 0 or greater than 106.**

D2. What language or languages do you speak with your family and friends? **[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**

- 1 English
- 2 Spanish
- 3 Arabic
- 4 Chinese
- 5 French
- 6 Hindi
- 7 Korean
- 8 Polish
- 9 Russian
- 10 Tagalog
- 11 Vietnamese
- 12 Other (*Specify* \_\_\_\_\_)
- 13 Other (*Specify* \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

D3. Do you consider yourself to be Hispanic or Latino/a?

- 0 No.....*Skip to D4*
- 1 Yes
- 7 Refused to answer.....*Skip to D4*
- 8 Don't know.....*Skip to D4*

D3a. What best describes your Hispanic ancestry? **[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**

- 1 Mexican
- 2 Puerto Rican
- 3 Cuban
- 4 Dominican
- 5 Other (*Specify:* \_\_\_\_\_)

- 6 Other (*Specify:* \_\_\_\_\_)
- 7 Refused to answer
- 8 Don't know

**Interviewer instructions: If respondent indicates a non-Hispanic ethnicity say, "When I say Hispanic ancestry I mean your origins can be traced to Mexico, Puerto Rico, Cuba, Central or South America, or other Spanish cultures."**

- D4. Which racial group or groups do you consider yourself to be in? You may choose more than one. **[READ CHOICES. CHOOSE ALL THAT APPLY.]**
- 1 Asian
  - 2 Black or African American
  - 3 American Indian or Alaskan Native
  - 4 Native Hawaiian or other Pacific Islander
  - 5 White
  - 6 Other (*Specify:* \_\_\_\_\_)
  - 7 Other (*Specify:* \_\_\_\_\_)
  - 77 Refused to answer
  - 88 Don't know
- D5. What is the highest level of education you completed? **[DON'T READ CHOICES. CHOOSE ONE.]**
- 1 Never attended school
  - 2 Grades 1 through 8
  - 3 Grades 9 through 11
  - 4 Grade 12 or high school diploma equivalency (GED)
  - 5 Some college, associate's degree, or technical degree
  - 6 Bachelor's degree
  - 7 Any post-graduate studies
  - 77 Refused to answer
  - 88 Don't Know
- D6. What was your sex at birth? **[READ CHOICES EXCEPT "INTERSEX/AMBIGUOUS" CHOOSE ONE.]**
- 1 Male
  - 2 Female
  - 3 Intersex/ambiguous
  - 7 Refused to answer
- D7. Do you consider yourself to be male, female, or transgender? **[CHOOSE ONE.]**
- 1 Male
  - 2 Female
  - 3 Transgender
  - 7 Refused to answer
  - 8 Don't know
- D8. Do you think of yourself as? **[READ CHOICES EXCEPT "OTHER." CHOOSE ONE.]**
- 1 Homosexual, Gay, or Lesbian
  - 2 Heterosexual or Straight
  - 3 Bisexual
  - 4 Other (*Specify* \_\_\_\_\_)
  - 7 Refused to answer
  - 8 Don't know

**SAY: "Now I am going to ask you some questions about the past 3 months."**

**Interviewer instructions: Show respondent calendar.**



D9. **During the past 3 months**, have you had any kind of health insurance or health care coverage? This includes Medicaid and Medicare.

- 0 No.....*Skip to D10*
- 1 Yes
- 7 Refused to answer.....*Skip to D10*
- 8 Don't know.....*Skip to D10*

D9a. **During the past 3 months**, what are all the kinds of health insurance or health care coverage you have had? **[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**

- 1 Private health insurance or health maintenance organization (HMO)
- 2 Medicaid
- 3 Medicare
- 4 Tricare or Champus
- 5 Veterans Administration or military coverage
- 6 Some other health insurance (*Specify: \_\_\_\_\_*)
- 7 Some other health insurance (*Specify: \_\_\_\_\_*)
- 77 Refused to answer
- 88 Don't know

**Interviewer note: Interviewers should be aware of any local names of government insurance programs.**

D9b. **During the past 3 months**, was there a time that you didn't have any health insurance or health care coverage?

- 0 No
- 1 Yes
- 7 Refused to answer
- 8 Don't know

D10.

	<b>During the past 3 months, have you:</b>	<b>No</b>	<b>Yes</b>	<b>Refused to answer</b>	<b>Don't know</b>
a.	...lived on the street?				
b.	...lived in a shelter?				
c.	...lived in a Single Room Occupancy (SRO) hotel				
d.	...lived in a car?				
e.	...lived with friends?				

D11. **During the past 3 months**, have you been in jail, detention, or prison for longer than 24 hours?

- 0 No
- 1 Yes
- 7 Refused to answer
- 8 Don't know

D12. What best describes your current employment status? Are you: **[READ CHOICES. CHOOSE ONE.]**

- 1 Unemployed
- 2 Working occasionally
- 3 Employed part-time (less than 35 hours per week)
- 4 Employed full-time (35 or more hours per week)
- 5 A full-time homemaker
- 7 Refused to answer
- 8 Don't know

- D13 Are you currently a student?
- 0 No
  - 1 Yes
  - 7 Refused to answer
  - 8 Don't know

**SAY:** "Now I would like to ask you some questions about 2006. That is January 1st, 2006 to December 31st, 2006."

**Interviewer instructions: Show respondent calendar.**

- D14 In **2006**, where did most of your money or financial support come from? **[DON'T READ CHOICES. CHOOSE ONE.]**
- 1 Salary or Wages
  - 2 Savings or investments
  - 3 Pension or retirement fund
  - 4 Social Security Supplemental Income or Disability Insurance (SSI or SSDI)
  - 5 Public assistance ("welfare")
  - 6 Spouse, partner, or family
  - 7 Friends
  - 8 Illegal or possibly illegal activities
  - 9 No income or financial support.....*Skip to Say box before C1a*
  - 10 Other (*Specify:* \_\_\_\_\_)
  - 77 Refused to answer
  - 88 Don't know

- D15 In **2006**, what was your household income from all sources before taxes? **[DON'T READ CHOICES.]**

**Interviewer note: Household income refers to the total amount of money from all people living in the household.**

**Interviewer instructions: Show Response Card A.**

**SAY:** "Please take a look at this card and tell me either your monthly or yearly income."

<u>Monthly Income</u>	<u>Yearly Income</u>
1 \$0 to \$417	1 \$0 to \$4,999
2 \$418 to \$833	2 \$5,000 to \$9,999
3 \$834 to \$1250	3 \$10,000 to \$14,999
4 \$1251 to \$1667	4 \$15,000 to \$19,999
5 \$1668 to \$2500	5 \$20,000 to \$29,999
6 \$2501 to \$3333	6 \$30,000 to \$39,999
7 \$3334 to \$4167	7 \$40,000 to \$49,999
8 \$4168 to \$6250	8 \$50,000 to \$74,999
9 \$6251 or more	9 \$75,000 or more
77 Refused to answer	77 Refused to answer
88 Don't Know	88 Don't Know

- D16 Including you, how many people depended on this income in **2006**? **[MUST BE AT LEAST 1.]**

— —

77 Refused to answer

**Inconsistency check:** D16 cannot be less than 1 or greater than 76.

## **BARRIERS TO HIV MEDICAL CARE**

**SAY:** Now I'm going to read you a list of reasons why some people don't get HIV medical care. Please tell me if the following are reasons why you didn't get HIV medical care **during the past 3 months**. Answer yes or no to each question.

	Was one of the reasons you didn't get HIV medical care during the past 3 months:	No	Yes	Refused to answer	Don't know
C1a.	Because you felt good?				
C1b.	Because you didn't believe that you were infected with HIV?				
C1c.	Because you didn't want to think about being HIV positive?				
C1d.	Because you didn't want to tell anyone that you have HIV?				
C1e.	Because you didn't have enough money or health insurance?				
C1f.	Because of responsibilities such as child care or work?				
C1g.	Because you were living on the street, in a shelter, in a car, or in a SRO (single room occupancy hotel)?				
C1h.	Because you felt depressed?				
C1i.	Because you were drinking or using drugs?				
C1j.	Because you felt too sick?				
C1k.	Because there is no cure?				
C1l.	Because you didn't believe HIV causes acquired immune deficiency syndrome (AIDS)?				
C1m.	Because of religious reasons.				
C1n.	Because you believed the medicines would do more harm than good or would be unpleasant?				
C1o.	Because you shared HIV prescription medicines with someone else?				
C1p.	Because you didn't like or trust health care workers?				
C1q.	Because you had trouble getting transportation to a clinic or doctor's office?				
C1r.	Because the location of the clinic or doctor's office was inconvenient?				
C1s.	Because the clinic hours were inconvenient?				

	Was one of the reasons you didn't get HIV medical care during the past 3 months:	No	Yes	Refused to answer	Don't know
C1t.	Because you couldn't get an appointment?				

**Interview instructions: If response to D2 is "English," skip to C2.**

C1u. Because no one at the clinic or doctor's office spoke your language?

C2. Are there any other reasons why you didn't get HIV medical care **during the past 3 months?**

- 0 No
- 1 Yes (*Specify*\_\_\_\_\_)
- 7 Refused to answer
- 8 Don't know

C3. Of all the reasons we just talked about, what was the main reason you didn't get HIV medical care **during the past 3 months? [DON'T READ CHOICES. CHOOSE ONLY ONE.]**

- 1 Felt healthy
- 2 Denial of status
- 3 Avoidance of status
- 4 Disclosure issues
- 5 Lack of money or health insurance
- 6 Other responsibilities
- 7 Homelessness
- 8 Mental health
- 9 Substance use
- 10 Felt sick
- 11 No cure
- 12 Disbelief that HIV causes AIDS
- 13 Religious reasons
- 14 HIV medicines harmful or unpleasant
- 15 Sharing HIV prescription medications
- 16 Dislike or lack of trust in health care workers
- 17 Transportation problems
- 18 Inconvenient clinic hours
- 19 Inconvenient clinic location
- 20 Appointment not available
- 21 Language barrier
- 22 Other (*Specify*\_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

C4. How likely is it that you will start HIV medical care **within the next 3 months? [READ CHOICES. CHOOSE ONE. SHOW RESPONSE CARD D.]**

- 1 Very unlikely to start care within the next 3 months
- 2 Fairly unlikely to start care within the next 3 months
- 3 Fairly likely to start care in within the next 3 months
- 4 Very likely to start care in within the next 3 months...*Skip to Say box before N1*
- 7 Refused to Answer.....*Skip to Say box before N1*
- 8 Don't know.....*Skip to Say box before N1*

C4a. What, if anything, would make you more likely to start HIV medical care **within the next 3 months?** You may give more than one answer. **[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**

- 1 If respondent felt sick
- 2 Sufficient money or health insurance
- 3 Concerns addressed about status being disclosed

- 4 Other responsibilities covered
- 5 Stable living situation
- 6 Sound mental health
- 7 Substance use recovery
- 8 Cure for HIV/AIDS discovered
- 9 HIV medicines that are not harmful or unpleasant
- 10 Likeable or trustworthy health care workers
- 11 Transportation available
- 12 Convenient clinic hours
- 13 Convenient clinic location
- 14 Available appointments
- 15 Services available in respondent's primary language
- 16 Nothing would make the respondent more likely to start HIV care
- 17 Other (*Specify*\_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

**Interviewer instructions: If C4a is "Refused to answer," "Don't know," or "Nothing would make the respondent more likely to start HIV care," skip to Say box before N1. If there is only one response for C4a, skip to Say box before N1.**

C4b. Of the answers you just gave, what is the most important one? **[DON'T READ CHOICES. CHOOSE ONLY ONE.]**

- 1 If respondent felt sick
- 2 Sufficient money or health insurance
- 3 Concerns addressed about status being disclosed
- 4 Other responsibilities covered
- 5 Stable living situation
- 6 Sound mental health
- 7 Substance use recovery
- 8 Cure for HIV/AIDS discovered
- 9 HIV medicines that are not harmful or unpleasant
- 10 Likeable or trustworthy health care workers
- 11 Transportation available
- 12 Convenient clinic hours
- 13 Convenient clinic location
- 14 Available appointments
- 15 Services available in respondent's primary language
- 16 Other (*Specify*\_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

**UNMET NEED**

**SAY:** “Now I’m going to ask about services you used or needed **during the past 3 months.**” [*SHOW RESPONDENT CALENDAR*]

**Interviewer instructions:** *If response to N1a is “No,” go to N1b; otherwise, skip to N2a. If response to N1b is “Yes,” go to N1c; otherwise, skip to N2a. Follow the same pattern for N1–N18.*

	During the past 3 months, did you get:	<b>IF “NO” IN N1A–N18A, ASK:</b> During the past 3 months, have you needed:	<b>IF “YES” IN N1B–N18B, ASK:</b> What was the main reason you haven’t been able to get this service during the past 3 months? <b>CODE: SEE CODE LIST BELOW FOR RESPONSES. [DON’T READ CHOICES. CHECK ONLY ONE]</b>
	<b>CODE:</b> <i>No = 0, Yes = 1, Refused to answer= 7, Don’t know = 8</i>	<b>CODE:</b> <i>No = 0, Yes = 1, Refused to answer= 7, Don’t know = 8</i>	
N1. Medical care for any reason	a. [_____]	b. [_____]	c. [_____]
N2. HIV case management services	a. [_____]	b. [_____]	c. [_____]
N3. Education or information about HIV	a. [_____]	b. [_____]	c. [_____]
N4. HIV peer group support	a. [_____]	b. [_____]	c. [_____]
N5. Dental care	a. [_____]	b. [_____]	c. [_____]
N6. Mental health services	a. [_____]	b. [_____]	c. [_____]
N7. Drug or alcohol counseling or treatment	a. [_____]	b. [_____]	c. [_____]
N8. Public benefits including Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI)	a. [_____]	b. [_____]	c. [_____]
N9. Transportation assistance	a. [_____]	b. [_____]	c. [_____]
N10. Domestic violence services	a. [_____]	b. [_____]	c. [_____]
N11. Shelter or housing services	a. [_____]	b. [_____]	c. [_____]
N12. Home health services			

- |      |                           |            |            |            |
|------|---------------------------|------------|------------|------------|
| N13. | Meal or food services     | a. [_____] | b. [_____] | c. [_____] |
|      |                           | a. [_____] | b. [_____] | c. [_____] |
| N14. | Job placement or training | a. [_____] | b. [_____] | c. [_____] |
| N15. | Childcare services        | a. [_____] | b. [_____] | c. [_____] |

**Interviewer instructions: If response to D2 is "English," skip to N17.**

- |      |  |            |            |            |
|------|--|------------|------------|------------|
| N16. | Interpreter services                           | a. [_____] | b. [_____] | c. [_____] |
| N17. | Legal assistance                               | a. [_____] | b. [_____] | c. [_____] |
| N18. | Other HIV-related services<br>(Specify: _____) | a. [_____] | b. [_____] | c. [_____] |

**Interviewer instructions: For N1c–N18c: [DON'T READ CHOICES. CHECK ONLY ONE.]**

- 1 Didn't know where to go or whom to call
- 2 Didn't complete application process
- 3 Waiting list is too long
- 4 Service isn't available
- 5 Not eligible or denied services
- 6 Service hours are inconvenient
- 7 Service costs too much/lack of insurance
- 8 Transportation problems
- 9 Language barrier
- 10 Too sick to get service
- 11 Other (Specify \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

## HIV TESTING

**SAY:** “Now I am going to ask you some questions about getting tested for HIV. To begin, I will ask questions about the **first** time you tested positive. Earlier you told me that you first tested positive on *[INSERT RESPONSE FROM E3]*. These next questions refer to that test.”

H1. The **first** time you tested positive, where were you tested for HIV?  
**[READ CHOICES. CHOOSE ONE. SHOW RESPONSE CARD E.]**

- 1 HIV counseling and testing site
- 2 Sexually transmitted disease (STD) clinic
- 3 HIV/AIDS or infectious disease clinic
- 4 Tuberculosis (TB) clinic
- 5 Drug and alcohol treatment clinic
- 6 Prenatal or family planning clinic
- 7 Private physician or HMO
- 8 Community health center
- 9 Health department
- 10 Mobile test site (health department van, needle exchange, etc.)
- 11 Emergency room
- 12 Inpatient hospital
- 13 Outpatient hospital
- 14 Jail, prison, or detention facility
- 15 Blood bank
- 16 Homeless shelter
- 17 Military facility
- 18 Other (*Specify:* \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

H1a. In what city and state did you get this test? If the **first** time you tested positive was outside the U.S., please tell me the country where you were tested.

\_\_\_\_\_ / \_\_\_\_\_  
(City) (State)

\_\_\_\_\_  
(Country)

- 7 Refused to answer
- 8 Don't know

H2. The **first** time you tested positive, did someone else recommend you get tested, did you decide to get tested yourself, or was the test required? **[READ CHOICES. CHOOSE ONE.]**

- 1 Someone else recommended it
- 2 You decided yourself to get tested.....*Skip to H3*
- 3 The test was required.....*Skip to H2b*
- 7 Refused to answer..... *Skip to H3*
- 8 Don't know.....*Skip to H3*

H2a. The **first** time you tested positive, who recommended you get tested? **[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**

- 1 Doctor, nurse, or other health care worker
- 2 Sexual partner
- 3 Family member or friend
- 4 Someone from the health department (partner notification)
- 5 Counselor



- 6 Peer educator
- 7 Other (*Specify:* \_\_\_\_\_)
- 8 Other (*Specify:* \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

**Interviewer instructions: Skip to H4**

H2b. The **first** time you tested positive, why were you required to get this test? [**DON'T READ CHOICES. CHOOSE ONE.**]

- 1 Insurance
- 2 Military
- 3 Jail
- 4 Hospitalization
- 5 Employment
- 6 Blood donation
- 7 Immigration
- 8 Ordered by the court
- 9 Other (*Specify:* \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

**Interviewer instructions: Skip to H4**

H3. The **first** time you tested positive, what was the main reason you decided to get tested? [**DON'T READ CHOICES. CHOOSE ONE.**]

- 1 Was ill
- 2 Was an injection drug user (IDU)
- 3 Man who had sex with men (MSM)
- 4 Had multiple sex partners
- 5 Wanted to stop using condoms with partner(s)
- 6 Was worried about infecting sex partner(s)
- 7 Sex partner was worried I might have HIV
- 8 Sex partner was HIV positive
- 9 Sex partner was an IDU
- 10 Sex partner was a MSM
- 11 Sex partner had multiple sex partners
- 12 Needle sharing partner was HIV positive
- 13 Friends were getting tested
- 14 Needle stick follow-up or occupational exposure
- 15 Offered as a screening test at a clinic (like STD, family planning, etc.)
- 16 Routine check-up or physical exam
- 17 Pregnancy
- 18 Paid to get tested
- 19 Read, saw, or heard something that made the respondent want to get tested
- 20 Wanted to know status
- 21 **Other** (*Specify:* \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

H4. The **first** time you tested positive, what type of test did you have? [**READ CHOICES. CHOOSE ONE.**]

- 1 An anonymous test, where you didn't give your name or you used a code
- 2 A confidential test, where you gave your name for identification
- 7 Refused to answer
- 8 Don't know

- H4a. Was this test a rapid test where you got your results the same day?
- 0 No
  - 1 Yes
  - 7 Refused to answer
  - 8 Don't know

**SAY:** "Now I would like to ask you some questions about your experience with an HIV counselor."

**Interviewer note: Questions H5–H9 refer to HIV post-test counseling. If the respondent has difficulty with the term 'counselor', say: "When I say 'counselor' I mean someone who may have spoken with you about your infection when you were first told you tested positive for HIV, such as a trained advisor or health care worker."**

- H5. When you were **first** told you tested positive for HIV, did you receive counseling?
- 0 No.....*Skip to Say box before B1*
  - 1 Yes
  - 7 Refused to answer.....*Skip to Say box before B1*
  - 8 Don't know.....*Skip to Say box before B1*

- H6. Did you feel your counselor spent enough time with you?
- 0 No
  - 1 Yes
  - 7 Refused to answer
  - 8 Don't know

- H7. When you were **first** told you tested positive for HIV, were you told where you could go for HIV medical care?
- 0 No
  - 1 Yes
  - 7 Refused to answer
  - 8 Don't know

- H8. When you were **first** told you tested positive for HIV, did anyone try to help you get into HIV medical care?
- 0 No.....*Skip to H9*
  - 1 Yes
  - 7 Refused to answer.....*Skip to H9*
  - 8 Don't know.....*Skip to H9*

- H8a. Who was that person or persons? **[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**
- 1 A counselor
  - 2 A social worker
  - 3 A case manager or other professional
  - 4 A family member or friend
  - 5 Other (*Specify*\_\_\_\_\_)
  - 6 Other (*Specify*\_\_\_\_\_)
  - 7 Refused to answer
  - 8 Don't know

**Interviewer instructions: Skip to Say box before B1.**

- H9. Has anyone **ever** tried to help you get into HIV medical care?
- 0 No.....*Skip to Say box before B1*
  - 1 Yes
  - 7 Refused to answer.....*Skip to Say box before B1*
  - 8 Don't know.....*Skip to Say box before B1*

H9a. Who was that person or persons? ***[DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]***

- 1 A counselor
- 2 A social worker
- 3 A case manager or other professional
- 4 A family member or friend
- 5 Other (*Specify*\_\_\_\_\_)
- 6 Other (*Specify*\_\_\_\_\_)
- 7 Refused to answer
- 8 Don't know

## CARE-SEEKING BEHAVIOR

**SAY:** “Now, I’m going to ask you some questions about **any** health care you may have received in the past.”

B1. Have you **ever** seen a doctor, nurse, or other health care worker for **any** medical problem other than HIV?

- 0 No.....*Skip to Say box before B6*  
 1 Yes  
 7 Refused to answer..... *Skip to Say box before B6*  
 8 Don’t know..... *Skip to Say box before B6*

B1a. What month and year did you **last** see a doctor, nurse, or other health care worker for **any** medical problem other than HIV?

\_\_\_ / \_\_\_  
 M M Y Y Y Y

[Month: 77 = Refused to answer, 88= Don’t know;  
 Year: 7777 = Refused to answer, 8888 = Don’t know]

**Interviewer note:** If respondent has difficulty remembering the date, suggest key dates and seasons to narrow the time period (i.e. “Was it in the winter or summer?”)

**Inconsistency check:** B1a cannot be **earlier than** the respondent’s date of birth (E1) or **later than** current date.

B2. Has a doctor, nurse, or other health care worker **ever** told you that you had hepatitis?

- 0 No.....*Skip to Instructions before B3*  
 1 Yes  
 7 Refused to answer..... *Skip to Instructions before B3*  
 8 Don’t know..... *Skip to Instructions before B3*

**B2a. What type or types of hepatitis have you had?** [READ CHOICES.]

	No	Yes	Refused to answer	Don’t know
a. Hepatitis A				
b. Hepatitis B				
c. Hepatitis C				
d. Other( <i>Specify:</i> _____)				
e. Other( <i>Specify:</i> _____)				

**Interviewer instructions:** If response to B1a is more than 3 months from date of interview (P6), skip to B5.

**SAY:** “Now I am going to ask you some questions about the past 3 months.” [SHOW RESPONDENT CALENDAR.]

B3. **During the past 3 months**, how many times did you go to an emergency room or urgent care center for any care?

\_\_\_

777 Refused to answer  
888 Don't know

**Interviewer note: Urgent care is defined as the delivery of care outside of a hospital emergency department on a walk-in basis. Urgent care centers include private medical centers and facilities intended for episodic treatment of medical conditions and not ongoing care.**

**Inconsistency check: B3 cannot be less than 0 or greater than 90.**

B4. **During the past 3 months, how did you pay for your medical costs? [DON'T READ CHOICES. CHOOSE ALL THAT APPLY.]**

- 1 Didn't pay
- 2 Paid out of pocket
- 3 Family or friend paid out of pocket
- 4 Private health insurance or HMO
- 5 Medicaid
- 6 Medicare
- 7 Tricare or Champus
- 8 Veterans Administration or military coverage
- 9 Other (*Specify:* \_\_\_\_\_)
- 10 Other (*Specify:* \_\_\_\_\_)
- 77 Refused to answer
- 88 Don't know

B5. Do you have a place where you **usually** go to see a doctor, nurse, or other health care worker when you are sick?

- 0 No.....*Skip to Say box before B7*
- 1 Yes
- 7 Refused to answer.....*Skip to Say box before B7*
- 8 Don't know.....*Skip to Say box before B7*

B6. Do you have one person you think of as **your personal** doctor, nurse, or other health care worker?

- 0 No.....*Skip to Say box before B7*
- 1 Yes
- 7 Refused to answer.....*Skip to Say box before B7*
- 8 Don't know.....*Skip to Say box before B7*

B6a. Has this person **ever** talked to you about HIV?

- 0 No.....*Skip to Say box before B7*
- 1 Yes
- 7 Refused to answer.....*Skip to Say box before B7*
- 8 Don't know.....*Skip to Say box before B7*

B6b. Do you trust what this person has told you about HIV?

- 0 No
- 1 Yes
- 7 Refused to answer
- 8 Don't know

**SAY:** "Now I would like to ask you about complementary and alternative medicines. These are products (such as herbs) or practices (such as yoga). Although many people use these therapies, it is uncertain whether they are safe or work for HIV."

B7. Since you tested positive for HIV, have you taken or used any of the following complementary or alternative therapies specifically for your HIV infection?

	No	Yes	Refused to answer	Don't know
a.				
b.				
c.				
d.				
e.				
f.				
g.				
h.				
i.				
j.				
k.				

## **SOCIAL RELATIONSHIPS**

**SAY:** "Now I'd like to ask you some questions about people who might help or support you."

- S1. Do you personally know anyone who has HIV or AIDS, or who died of AIDS?
- 0 No.....*Skip to S2*
  - 1 Yes
  - 7 Refused to answer.....*Skip to S2*
  - 8 Don't know .....*Skip to S2*
- S1a. What is your relation to this person or these people? **[READ CHOICES. CHOOSE ALL THAT APPLY.]**
- 1 Family member(s)
  - 2 Friend(s)
  - 3 Other person(s)
  - 7 Refused to answer
  - 8 Don't know
- S2. Have you **ever** told anyone that you are HIV positive?
- 0 No.....*Skip to S3*
  - 1 Yes
  - 7 Refused to answer.....*Skip to S3*
  - 8 Don't know.....*Skip to S3*
- S2a. Not including health care workers, how many people have you told that you are HIV positive? **[READ CHOICES. CHOOSE ONE. SHOW RESPONSE CARD F.]**
- 1 None
  - 2 One person
  - 3 2-5 people
  - 4 6-10 people
  - 5 More than 10 people
  - 7 Refused to answer
  - 8 Don't know
- S2b. Not including health care workers, who have you told that you are HIV positive? **[READ CHOICES. CHOOSE ALL THAT APPLY.]**
- 1 Family member(s)
  - 2 Friend(s)
  - 3 Other person(s)
  - 7 Refused to answer
  - 8 Don't know

S3. **SAY:** “People sometimes look to others for companionship, assistance, or other types of support. Please tell me how often the following kinds of support are available to you if you need it. Would you say this is available never, rarely, about half the time, most of the time, or always?”

**Interviewer instructions: Show Response Card G.**

	Never	Rarely	About half the time	Most of the time	Always	Refused to answer	Don't know
a. Someone to give you good advice about a crisis.							
b. Someone to confide in or talk to about yourself or your problems.							
c. Someone who understands your problems.							

### **MODE OF INFECTION**

**SAY:** “Now I am going to ask you some questions about how you might have gotten HIV. To begin, I am going to ask you about having sex. For these questions, ‘having sex’ means oral sex (mouth on the vagina or penis), vaginal sex (penis in the vagina), or anal sex (penis in the anus).”

M1.

<b>Before</b> you tested positive for HIV, did you:	No	Yes	Refused to answer	Don't know
a. ...have sex with a man without a condom?				
b. ...have sex with a woman without a condom?				
c. ...have sex without a condom with someone who had HIV?				
d. ...receive a blood transfusion or organ transplant?				
e. ...have sex without a condom with someone who received a blood transfusion?				
f. ...receive blood products for a bleeding disorder?				
g. ...have sex without a condom with someone who received blood products for a bleeding disorder?				
h. ...work in a health care setting where you may have been exposed to blood?				
i. ...shoot up or inject any drugs that weren't used for medical purposes?				
j. ... have sex without a condom with someone who shot up or injected				



any drugs that weren't used for medical purposes?

**Interviewer instructions: If M1i is "Yes," go to M2; otherwise skip to end of interview.**

M2. In the **past 3 months**, have you shot up or injected any drugs that weren't used for medical purposes?

- 0 No
- 1 Yes
- 7 Refused to answer
- 8 Don't know

### HEALTH AND WELL-BEING

**SAY:** "The next questions ask for your views about your overall health; not just related to HIV. This information will help keep track of how you feel and how well you are able to do your usual activities."

W1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

[7 = Refused to answer]

W2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Yes, limited a lot	Yes, limited a little	No, not limited at all
▼	▼	▼

- a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?.....1.....2.....3
- b. Climbing several flights of stairs?.....1.....2.....3

[7 = Refused to answer]

W3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
-----------------	------------------	------------------	----------------------	------------------

▼      ▼      ▼      ▼      ▼

a Accomplished less than you would like?.....1.....2.....3.....4.....5

b Were limited in the kind of work or other activities?.....1.....2.....3.....4.....5

[7 = Refused to answer]

W4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
-----------------	------------------	------------------	----------------------	------------------

▼      ▼      ▼      ▼      ▼

a Accomplished less than you would like?.....1.....2.....3.....4.....5

b Did work or other activities less carefully than usual?.....1.....2.....3.....4.....5

[7 = Refused to answer]

W5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

[7 = Refused to answer]

W6. *These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...*

All of the time	Most of the time	Some of the time	A little of the time	None of the time
-----------------	------------------	------------------	----------------------	------------------

▼      ▼      ▼      ▼      ▼

a Have you felt calm and peaceful?.....1.....2.....3.....4.....5

b Did you have a lot of energy?.....1.....2.....3.....4.....5

c Have you felt downhearted and depressed?1.....2.....3.....4.....5

[7 = Refused to answer]

W7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

[7 = Refused to answer]

**Time questionnaire ended:**

**Time questionnaire ended:**  
\_\_ : \_\_ AM PM

## **INTERVIEW COMPLETION**

**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:***

***Ask if the respondent has any questions.***

***Offer information and resources as indicated in the protocol.***

***If the interview was discontinued because the respondent is < 18 years old, lives outside the survey area, has received medical care for HIV, or has never been told his/her HIV status, don't pay the respondent.***

***If the interview was discontinued because the interview was partially or fully completed, pay the respondent and have him/her sign the receipt.***

**SAY:** “To learn how to make HIV services better and more available to people living with HIV/AIDS in this community, we would like to talk with others in your community. If you know anyone who is HIV infected and has never had medical care for their HIV infection, we ask that you tell them about this project if you are comfortable doing so, and encourage them to call us about taking part in the survey. If a person you have told about the project calls us, we will check to see if he or she is eligible to be interviewed. If you wish, we have written information about this project that we can give you now to give others who might be interested in telling us about their experiences.”

***Interviewer Instructions:*** Give the respondent enough copies of the flyer about NIC to give to others he/she is considering referring to the project.

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

### **Payment Verification**

- F1. Payment made:
- |           |   |                     |
|-----------|---|---------------------|
| No.....   | 0 |                     |
| Yes ..... | 1 | → <b>Skip to F2</b> |
- F1a. Why was payment not made?
- |                                      |   |                     |
|--------------------------------------|---|---------------------|
| Respondent refused payment.....      | 1 | → <b>Skip to F3</b> |
| Other ( <i>Specify: _____</i> )..... | 2 | → <b>Skip to F3</b> |
- F2. Receipt signed (or initialed):
- |           |   |                     |
|-----------|---|---------------------|
| No.....   | 0 |                     |
| Yes ..... | 1 | → <b>Skip to F3</b> |

F2a. Why was receipt not signed?  
 Respondent refused to sign..... 1  
 Other (*Specify:*.....)..... 2

F3. How confident are you of the validity of the respondent's answers?  
 Confident..... 1  
 Some doubts..... 2  
 Not confident at all..... 3

F4. Record any additional comments, including disruptions that might have taken place during the interview, reason the interview might have been stopped, or why the respondent's answers may not have been reliable.

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