

ATLANTA EMA CONSUMER SURVEY OF PEOPLE LIVING WITH HIV AND AIDS

Sponsored by Ryan White Part A HIV Health Services Planning Council and Fulton County Government Ryan White Program

INTRODUCTION

Thank you for agreeing to take part in this survey. It will give you a voice in the planning of HIV and AIDS treatment services throughout Atlanta and surrounding Counties.

For each question on the survey, circle or write in an answer. There are no right or wrong answers. Please take as much time as you need to answer each question based on your experiences. If you have any questions or need help, please ask.

Your answers are completely private. Your name will never be linked to your answers.

Thank you in advance. Please continue.

Confidential ID Needed

We will be asking many people living with HIV and AIDS to answer these questions. Please create a private identifier for the top of every page. This ID is unique to you, and will protect your privacy.

What is the firstinitial of your first name

What is the lastinitial of your last name

What is the month of your birthday

What is the day of your birthday

What is the first letter of your mother's first name?
(If you don't know, list the first letter of your father's first name)

(01=Jan, 02=Feb, 03=Mar, 04=Apr, 05=May, 06=Jun, 07=Jul, 08=Aug, 09=Sep, 10=Oct, 11=Nov, 12=Dec)

Please copy the ID you have created on the top right of each page of the survey.

Interviewer Initials:

Location of Interview:

Today's Date: ____/____/____

1. This survey is ONLY for people living with HIV/AIDS. Do you know your HIV status? (Select only 1)	
I am HIV positive (<i>Go to the next question</i>)	<input type="checkbox"/>
I have AIDS (<i>Go to the next question</i>)	<input type="checkbox"/>
I am HIV negative (<i>STOP</i>)	<input type="checkbox"/>
I don't know (<i>STOP</i>)	<input type="checkbox"/>

2. What is the zip code and County where you live?	_____
<input type="checkbox"/> Check here if you are currently homeless	

3. When were you born?	_____/____
	Month Year

4. What is your gender? (Select 1 answer)	
Male	<input type="checkbox"/>
Female	<input type="checkbox"/>
Transgender – Male to female (MTF)	<input type="checkbox"/>
Transgender – Female to male (FTM)	<input type="checkbox"/>
Other (Explain) _____	<input type="checkbox"/>

5. What is your ethnic background? (Select all that apply)	
American Indian/Alaska Native	<input type="checkbox"/>
Asian/Pacific Islander	<input type="checkbox"/>
Black/African American (non-Hispanic)	<input type="checkbox"/>
Hispanic/Latino	<input type="checkbox"/>
White/Caucasian (non-Hispanic)	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

5a. If not English, what other language do you speak most frequently at home?	_____
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6. Do you consider yourself:(Select 1 answer)	
Heterosexual/Straight	<input type="checkbox"/>
Homosexual – Gay Male	<input type="checkbox"/>
Lesbian	<input type="checkbox"/>
Bisexual	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

7. What is the highest grade you completed? (Select 1 answer)	
Grade school or less	<input type="checkbox"/>
Some high school	<input type="checkbox"/>
Graduated high school/GED	<input type="checkbox"/>
Some college/2 yr college/trade school	<input type="checkbox"/>
Completed 4 year college	<input type="checkbox"/>
Graduate school	<input type="checkbox"/>

8. Where do you currently live? (Select 1 answer)	
In an apartment/house I own	<input type="checkbox"/>
In an apartment/house I rent	<input type="checkbox"/>
At my parent's/relative's apt./house	<input type="checkbox"/>
Living/crashing with someone and not paying rent	<input type="checkbox"/>
Single room occupancy (SRO) <u>with</u> tenancy/hotel	<input type="checkbox"/>
Single room occupancy (SRO) <u>without</u> tenancy	<input type="checkbox"/>
In a housing program	<input type="checkbox"/>
In a treatment facility (drug or psych)	<input type="checkbox"/>
In a half-way house	<input type="checkbox"/>
Skilled nursing home (assisted living facility)	<input type="checkbox"/>
Homeless (on the street/in a car)	<input type="checkbox"/>
Homeless Shelter	<input type="checkbox"/>
Hospice	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

9. Does the government or another organization currently pay or help pay for your housing?	
<input type="checkbox"/> No	
<input type="checkbox"/> Not sure	
<input type="checkbox"/> Homeless	
<input type="checkbox"/> Yes (Select all that apply)	
<input type="checkbox"/> Section 8	
<input type="checkbox"/> HOPWA	
<input type="checkbox"/> Live in public housing	
<input type="checkbox"/> Live in a home for PLWHA	
<input type="checkbox"/> Getting help, not sure what it's called	
<input type="checkbox"/> Other type of help	

10. How long have you lived at your current residence?	
Less than one month	<input type="checkbox"/>
One to two months	<input type="checkbox"/>
Three to six months	<input type="checkbox"/>
Six months to one year	<input type="checkbox"/>
More than one year	<input type="checkbox"/>

11. At any time in the last 2 years, have you needed any of these services? (Select all that apply)	
Help finding a place to live	<input type="checkbox"/>
Permanent housing	<input type="checkbox"/>
Short-term housing (<i>i.e., halfway house, homeless shelter, single room occupancy</i>)	<input type="checkbox"/>
Housing where my child(ren) can live with me	<input type="checkbox"/>
Nursing home, drug/psych treatment	<input type="checkbox"/>
Money to pay utilities	<input type="checkbox"/>

Money to pay rent/mortgage	<input type="checkbox"/>
House for PLWH/A (Assisted Living)	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>
None of the above	<input type="checkbox"/>

12. Thinking about your housing now: do any of these stop you from taking care of your HIV/AIDS?(Select all that apply)

I don't have a safe and/or private room	<input type="checkbox"/>
I don't have a bed to sleep in	<input type="checkbox"/>
I don't have a place to store my medications	<input type="checkbox"/>
I don't have a telephone where someone can call me	<input type="checkbox"/>
I don't have enough food to eat	<input type="checkbox"/>
I don't have money to pay for rent	<input type="checkbox"/>
I don't have heat and/or air conditioning	<input type="checkbox"/>
I'm afraid of others knowing I am HIV+	<input type="checkbox"/>
I can't get away from drugs	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

13. How many people live with you? (Write in the number)

Other adults	_____
Children and teens	_____
<i>If you do not live with anyone, skip to Q. 14</i>	

13a. Is anyone else in your household HIV+?
Interviewer: Read and provide a response for each item below.

Partner/wife/husband	Y	N	DK
Adult family member/relative	Y	N	DK
Other adults-not relatives	Y	N	DK
Children	Y	N	DK

14. Have you been in jail or prison for more than one month during the last year?

Yes → Ask Q. 15, 16, and 17	<input type="checkbox"/>
No → Go to Q. 18	<input type="checkbox"/>

15. Did you receive HIV medical care while in jail or prison?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

16. After you were released from jail or prison, did you receive:(Select all that apply)

Information about finding housing	<input type="checkbox"/>
Referral to medical care	<input type="checkbox"/>

A supply of HIV medicine to take with you

<input type="checkbox"/>	
Referral to a case manager	<input type="checkbox"/>
Information about other services	<input type="checkbox"/>
None of the above	<input type="checkbox"/>

17. If you did not get the HIV/AIDS services you needed after you were released, why not? (Select all that apply)

No insurance-money reasons	<input type="checkbox"/>
I didn't know where to go	<input type="checkbox"/>
I didn't want anyone to know I have HIV	<input type="checkbox"/>
I couldn't get away from drugs/alcohol	<input type="checkbox"/>
I had trouble finding people I could trust	<input type="checkbox"/>
I didn't have a way to get to services	<input type="checkbox"/>
I didn't have ID or documentation to qualify	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

18. What best describes your current job (work) situation? (Select 1 answer)

Work full-time (32-40 hrsprwk)	<input type="checkbox"/>
Work part-time (less than 32 hrswk)	<input type="checkbox"/>
Working part time and on disability	<input type="checkbox"/>
On disability – looking for work	<input type="checkbox"/>
Not working – on full disability	<input type="checkbox"/>
Not working –seeking work	<input type="checkbox"/>
Not working	<input type="checkbox"/>
Student/homemaker/volunteer	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

19. What is your estimated yearly income before taxes?(Select 1 answer)

\$0 - \$10,890 (up to \$907 a month)	<input type="checkbox"/>
\$10,891-\$16,090 (\$908-\$1341 a month)	<input type="checkbox"/>
\$16,091-\$21,290 (\$1342-\$1774 a month)	<input type="checkbox"/>
\$21,291-\$26,490(\$1775-\$2207 a month)	<input type="checkbox"/>
\$26,491-\$31,690 (\$2208-\$2641 a month)	<input type="checkbox"/>
\$31,691-\$36,890(\$2642-\$3074 a month)	<input type="checkbox"/>
Greater than \$36,890 (\$3074 or more)	<input type="checkbox"/>

20. How many people are supported by this income? (write in number) _____

Of these, how many under 24? (write in number) _____
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21. Do you have health insurance?
Yes <input type="checkbox"/> → Go to Q. 21a
No <input type="checkbox"/> → Go to Q. 22

HICP – health insurance money	Y	N	DK
TANF	Y	N	DK
Other (Specify) _____	Y	N	DK

21a. What kind of health insurance do you have? <i>Interviewer: Read and provide a response for each item below</i>		
Insurance /HMO through work	Y	N
Insurance through my last job - COBRA	Y	N
Out-of-pocket/fee-for-service	Y	N
Private insurance/HMO not thru work	Y	N
Medicare	Y	N
Medicaid	Y	N
VA	Y	N
Other (Specify) _____	Y	N
Don't know	Y	N

24. What was the month and year that you first tested positive for HIV?	____/____
	Mo. Yr.

24a. In what city/state or country were you tested positive for HIV?

City State or Country

22. If NO health insurance: What is preventing you from getting health insurance? (Select all that apply)	
I cannot afford it	<input type="checkbox"/>
I do not know where to get it	<input type="checkbox"/>
I was denied because of previous medical condition	<input type="checkbox"/>
I did not have US residency proof	<input type="checkbox"/>
I don't qualify	<input type="checkbox"/>
It is not a priority for me at this time	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

25. When you tested positive for HIV, what type of HIV test did you have?	
Standard blood test	<input type="checkbox"/>
Oral test (oral swab)	<input type="checkbox"/>
Urine HIV antibody test	<input type="checkbox"/>
Rapid Blood Test (finger stick)	<input type="checkbox"/>
Home test	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

23. Which of these benefits do you receive? Provide a response for each item			
Food Stamps	Y	N	DK
Private long term disability	Y	N	DK
Private short term disability	Y	N	DK
SSI (Supplemental Security Income)	Y	N	DK
SSDI (Social Security Disability Income)	Y	N	DK
SDI (State Disability Insurance)	Y	N	DK
VA (Veteran's benefits)	Y	N	DK
CHAMPUS (VA assistance for non-military personnel)	Y	N	DK
Worker's compensation	Y	N	DK
Life Insurance	Y	N	DK
Retirement	Y	N	DK
Emergency Financial Assistance (Specify) _____	Y	N	DK
WIC-food for children	Y	N	DK
ADAP (AIDS Drug Assistance Program)	Y	N	DK

26. Were you ever tested for HIV <u>before</u> you tested positive for HIV?	
Yes → How many times? _____	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't remember	<input type="checkbox"/>

27. When you first tested positive, what was the main reason you decided to get tested? (Select 1 response)	
Had been feeling sick	<input type="checkbox"/>
Gift or money given for testing	<input type="checkbox"/>
Peer pressure from friends	<input type="checkbox"/>
Pressure from family members	<input type="checkbox"/>
Asked by a provider	<input type="checkbox"/>
Involved in sex work	<input type="checkbox"/>
Media campaigns	<input type="checkbox"/>
Asked by outreach worker	<input type="checkbox"/>
Easy access to testing site	<input type="checkbox"/>
No particular reason	<input type="checkbox"/>
Other (Specify) _____	<input type="checkbox"/>

28. Did you ever put off getting tested for HIV?	
No → Skip to Q. 29	<input type="checkbox"/>
Yes → Mark all that apply below	<input type="checkbox"/>
Fear of being positive	<input type="checkbox"/>
Fear of others finding out	<input type="checkbox"/>
Fear of having to take medicine	<input type="checkbox"/>

Fear of telling partner	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

29. How did you find out you had HIV? (Select 1 response)	
Requested a test for HIV	<input type="checkbox"/>
Donated blood	<input type="checkbox"/>
Went to the hospital or emergency room for something else	<input type="checkbox"/>
Part of doctor's visit	<input type="checkbox"/>
As part of care while pregnant	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

30. After testing positive for HIV, were you given a referral to a clinic?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

31. After testing HIV positive, when did you have your first visit with a doctor? (Select 1 answer)	
Within one month	<input type="checkbox"/>
Within six months of diagnosis	<input type="checkbox"/>
Six months to one year after diagnosis	<input type="checkbox"/>
If any of the next 3 apply, check response and continue to Q. 31a.	
Longer than one year after diagnosis	<input type="checkbox"/>
I have not seen a doctor for my HIV	<input type="checkbox"/>
I have chosen not to see a doctor	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

31a. Did you not receive care after diagnosis for any of the following reasons? (Select all that apply)	
I didn't know where to go	<input type="checkbox"/>
I couldn't get an appointment	<input type="checkbox"/>
I couldn't get transportation	<input type="checkbox"/>
I couldn't get child care	<input type="checkbox"/>
I couldn't pay for care	<input type="checkbox"/>
Not important to me	<input type="checkbox"/>
I didn't want anyone to know I had HIV	<input type="checkbox"/>
I didn't feel sick	<input type="checkbox"/>
Not enough doctors in my area	<input type="checkbox"/>
I couldn't get time off work	<input type="checkbox"/>
I was depressed	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

32. Who <u>first</u> helped you get into care after you found out you had HIV? (Select 1 response response)	
Family member	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Doctor/medical provider	<input type="checkbox"/>
Person who gave you test results	<input type="checkbox"/>
Case manager/social worker	<input type="checkbox"/>
Outreach worker from health department (i.e., DIS, CDS, Partner Services)	<input type="checkbox"/>
Prison/jail	<input type="checkbox"/>
Nobody	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

33. Were you ever told by your doctor or nurse, that you have AIDS?	
Yes → Answer Q. 33a	<input type="checkbox"/>
No	<input type="checkbox"/>
I had AIDS the same time I learned I had HIV	<input type="checkbox"/>

33a. When were you told that you had AIDS?	
_____/_____ Mon. Yr.	

34. What is the most likely way you were infected with HIV? (Select 1 answer)	
Sex with a man	<input type="checkbox"/>
Sex with a woman	<input type="checkbox"/>
Sharing needles	<input type="checkbox"/>
Blood transfusion	<input type="checkbox"/>
Acquired at birth	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

35. What was your most recent T-cell (CD4) count?	
Under 200	<input type="checkbox"/>
Between 200-350	<input type="checkbox"/>
Between 350-500	<input type="checkbox"/>
Over 500	<input type="checkbox"/>
Never had one/Never told results	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

36. When was the last time you had a t-cell count?	
In the last month	<input type="checkbox"/>

In the last 3 months	<input type="checkbox"/>
In the last 6 months	<input type="checkbox"/>
One year or more	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

I had mental health issues	<input type="checkbox"/>
I had a bad experience with medical staff	<input type="checkbox"/>
I had a bad experience with my medicine	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

37. What was your most recent viral load?	
Undetectable or below 50	<input type="checkbox"/>
Between 50 – 55,000	<input type="checkbox"/>
Over 55,000	<input type="checkbox"/>
Never had one/Never told results	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

41b. Since that time, have you gone back to see a doctor?	
Yes <input type="checkbox"/> → Go to Q. 41c	
No <input type="checkbox"/> → Go to Q. 42	

38. When was the last time you had a viral load test done?	
In the last month	<input type="checkbox"/>
In the last 3 months	<input type="checkbox"/>
In the last 6 months	<input type="checkbox"/>
One year or more	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

41c. If YES to Q. 41b, what happened to make you go back to care? (Select all that apply)	
I got sicker	<input type="checkbox"/>
Change in my income	<input type="checkbox"/>
Change in my insurance status	<input type="checkbox"/>
Heard about new doctor/clinic	<input type="checkbox"/>
Change in my doctor's or clinic's attitudes	<input type="checkbox"/>
Different drugs or treatments available	<input type="checkbox"/>
I had stable housing	<input type="checkbox"/>
I wanted to get a blood work	<input type="checkbox"/>
I was able to deal with other problems in my life	<input type="checkbox"/>
Someone helped me return to care	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

39. When was your last visit with a doctor, nurse, or other health care provider for your HIV/AIDS?	
I have never seen a doctor or gone to a clinic since I found out I was HIV+ (Skip to Q.45)	<input type="checkbox"/>
Less than 6 months ago	<input type="checkbox"/>
Six to twelve months ago	<input type="checkbox"/>
More than a year ago	<input type="checkbox"/>

42. At this time, where do you go for medical care most often? (Select 1 answer)	
HIV clinic in a hospital/medical center	<input type="checkbox"/>
Emergency Room	<input type="checkbox"/>
Community clinic that serves only HIV clients/HIV specialty clinic	<input type="checkbox"/>
Private doctor	<input type="checkbox"/>
Other community clinic	<input type="checkbox"/>
VA Hospital/clinic	<input type="checkbox"/>
I don't receive medical care	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

40. Since you found out you have HIV, has there been a period of time of more than one year when you didn't see a doctor or go to a clinic?	
Yes <input type="checkbox"/> → Go to Q. 41a	
No <input type="checkbox"/> → Go to Q. 42	

41a. What stopped you from seeking HIV care during that period? (Select all that apply)	
I couldn't afford care	<input type="checkbox"/>
I didn't know where to go	<input type="checkbox"/>
I wasn't ready to deal with my HIV	<input type="checkbox"/>
I didn't want others to know I had HIV	<input type="checkbox"/>
I was afraid of the medication side effects	<input type="checkbox"/>
I was in jail or prison	<input type="checkbox"/>
I couldn't get care where I lived	<input type="checkbox"/>
It was too confusing to get services	<input type="checkbox"/>
I had other concerns	<input type="checkbox"/>
I was homeless	<input type="checkbox"/>
I was using drugs or alcohol	<input type="checkbox"/>

43. Thinking about the past year, how often did you get medical care from a physician or clinician who can prescribe medications from a pharmacy?	
Never	<input type="checkbox"/>
Only when I was sick	<input type="checkbox"/>
On a regular ongoing basis	<input type="checkbox"/>

44. How many prescription drugs, including drugs not related to HIV, are you currently taking?	
Write number here: _____ # _____	

45. Are you taking any of the following? Please answer each item below			
Not currently on medications (Check box and skip to Q. 48)			<input type="checkbox"/>
HIV drugs: antiretrovirals, protease inhibitors	Y	N	DK
Other drugs related to HIV/AIDS (bactrim, dapsone, etc.)	Y	N	DK
Birth control pills	Y	N	DK
Other drugs you take every day (diabetes, cholesterol, high blood pressure)	Y	N	DK
Antidepressants or other mental health drugs	Y	N	DK
Pain or sleep aids	Y	N	DK
Hormones or steroids	Y	N	DK
TB medication	Y	N	DK
Hepatitis C drugs	Y	N	DK
Herbal or other over-the-counter products	Y	N	DK

46. Are any of your prescription drugs paid for or reimbursed by the following sources? Please answer each item			
ADAP (AIDS Drug Assistance Program)	Y	N	DK
Medicaid	Y	N	DK
Medicare	Y	N	DK
Veteran benefits	Y	N	DK
Private insurance	Y	N	DK
Pay myself	Y	N	DK
WellVista – free medicine from drug company	Y	N	DK
Other (Specify)_____	Y	N	DK

47. Are you currently on the waiting list for ADAP (AIDS Drug Assistance Program)?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

48. If you are not taking medicine to treat your HIV/AIDS, why not? If not on medications, select all that apply:	
I don't know where to get them	<input type="checkbox"/>
I can't afford the cost	<input type="checkbox"/>
They made me feel bad	<input type="checkbox"/>
I decided to take some time off medicine	<input type="checkbox"/>
I feel healthy	<input type="checkbox"/>
I have trouble remembering to take	<input type="checkbox"/>

my pills	
I have trouble understanding how to take my medications	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>
I do take medicine now (Check box and skip to Q. 49)	<input type="checkbox"/>

49. In the past 30 days, how often have you skipped taking your HIV/AIDS medicine?	
Once or twice in the past month	<input type="checkbox"/>
Once or twice a week	<input type="checkbox"/>
More than twice a week	<input type="checkbox"/>
I have stopped taking my medicine	<input type="checkbox"/>
Have not skipped in past 30 days (Check box and skip to Q. 51)	<input type="checkbox"/>
Not currently on medicine (Check box and skip to Q. 51)	<input type="checkbox"/>

50. If you skipped or stopped taking your HIV/AIDS medicine in the past 30 days, why? Read and provide a response for each item below		
Side effects	Y	N
Hard schedule to remember	Y	N
Didn't want others to see me taking HIV/AIDS medicine	Y	N
Didn't understand the directions	Y	N
Felt the medicines didn't work	Y	N
Couldn't afford medicine	Y	N
Forgot	Y	N
Ran out	Y	N
Hard to coordinate w/ food	Y	N
Just didn't want to take them	Y	N
Homeless	Y	N
Depressed/hopeless	Y	N
Medicine made me feel good so felt	Y	N
I didn't need them anymore	Y	N
My doctor advised me to stop	Y	N
Was away from home	Y	N
Had a change in my daily routine	Y	N
Felt the drug was toxic/harmful	Y	N
Other (Specify)_____	Y	N

51. Have you been told you have any of these infections? Please answer each item below			
Hepatitis A	Y	N	DK
Hepatitis B	Y	N	DK
Hepatitis C	Y	N	DK

51a.[If YES to Q.51] After testing positive for Hepatitis A, B, or C, were you sent to a Hepatitis expert? Y N DK

52. At any time in the last year, have you been told you have any of these infections?
Please answer each item below

Syphilis	Y	N	DK
Herpes	Y	N	DK
Genital Warts	Y	N	DK
Chlamydia	Y	N	DK
Gonorrhea	Y	N	DK
Yeast Infection	Y	N	DK
Other (Specify)_____			

53. Has a doctor **ever** told you that you have:
Please answer each item below

Diabetes or sugar diabetes	Y	N	DK
High blood cholesterol	Y	N	DK
Any kind of heart disease	Y	N	DK
Neuropathy (nerve pain)	Y	N	DK
Osteoporosis	Y	N	DK
Arthritis	Y	N	DK
Cancer	Y	N	DK
TB	Y	N	DK

54. Since you have had HIV, have you received mental health care of any kind?

Yes → Go to Q. 54a	<input type="checkbox"/>
No → Go to Q. 55	<input type="checkbox"/>

54a.What mental health care did you receive?
Please answer each item below

In a hospital at least overnight	Y	N
One to one counseling	Y	N
Group counseling	Y	N
Medicine	Y	N
Counseling on intimacy issues related to HIV and your partner	Y	N

55. At any time in the last 2 years have you been told you have: *Please answer each item below*

Anxiety	Y	N
Bipolar disorder	Y	N
Dementia	Y	N
Depression	Y	N
Other mental health (Specify)_____	Y	N

56. Since you have had HIV, have you received substance abuse care?

Yes → Go to Q. 56a	<input type="checkbox"/>
No → Go to Q. 57	<input type="checkbox"/>

56a.What substance abuse care did you receive?
Please answer each item below

In a hospital at least overnight	Y	N
One to one counseling	Y	N
Group counseling	Y	N
Medicine	Y	N

57. In general, would you say your health is...
(Select 1 answer)

Excellent	<input type="checkbox"/>
Very good	<input type="checkbox"/>
Good	<input type="checkbox"/>
Fair	<input type="checkbox"/>
Poor	<input type="checkbox"/>

58. Thinking about both physical illness and injury, for about how many days during the last month Was your physical health **not good**?

# of days _____	
None	<input type="checkbox"/>

59. Thinking stress, depression, and other emotional issues, for about how many days during the last month was your mental health **not good**?

# of days _____	
None	<input type="checkbox"/>

60. Do you currently have a HIV case manager (someone to help you coordinate your HIV/AIDS care?)

Yes → Go to Q. 67	<input type="checkbox"/>
No, I am self managed → Go to Q.61	<input type="checkbox"/>
No, not currently in care →Go to Q. 70	<input type="checkbox"/>
Not yet, waiting for first appointment →Go to Q. 68	<input type="checkbox"/>

61. Why did you decide to be self-managed?
Select all that apply

Personal preference	<input type="checkbox"/>
Advice of case manager	<input type="checkbox"/>
Unhappy with quality of case management services I was receiving.	<input type="checkbox"/>
Other (Specify)_____	<input type="checkbox"/>

62. In the <u>past 12 months</u> , have you been contacted by a case manager to <u>check on how you are doing</u> ?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

63. Do you <u>know how</u> to reach a case manager in case of an emergency or if you need additional support?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

64. In the <u>past 12 months</u> , have you had to contact a case manager to help you with an emergency need or to get services?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

65. Do you get invited to workshops or meetings for self-managed clients?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

66. In the <u>past 12 months</u> , have you attended activities, workshops, or meetings for self-managed clients?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

67. In the <u>past 12 months</u> , have you received a referral from a case manager for:	
Medicines	<input type="checkbox"/>
Support services	<input type="checkbox"/>
Other referrals (Specify) _____	<input type="checkbox"/>

68. In the <u>past 12 months</u> , have you received hospice services?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

69. In the <u>past 12 months</u> , have you received alternative treatments such as acupuncture, traditional Chinese medicine, or massage therapy?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

70. For each of the services in this next section:

- Under **Column A**, circle “yes” if you know that the service is available for people living with HIV/AIDS and “no” if you don’t know if it is available.
- Under **Column B**, note if you needed the service **in the past year**.
- Under **Column C**, note whether **received** the service **in the past year**.
- Under **Column D**, if you **received the service in the past year**, note if the service **met your needs**.

70a. PRIMARY CARE	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Primary Medical Care with a doctor, nurse or physician assistant to take care of your HIV	Yes No	Yes No	Yes No	Yes No
Treatment Adherence Counselor/Nurse – professional support to help you stay with your medication schedule	Yes No	Yes No	Yes No	Yes No
Nutrition Education and Counseling – nutritional supplements prescribed by a primary care provider	Yes No	Yes No	Yes No	Yes No

70b. ORAL HEALTH CARE	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Emergency Dental Care.	Yes No	Yes No	Yes No	Yes No
Preventive Dental Care (i.e., cleaning, xrays)	Yes No	Yes No	Yes No	Yes No
Treatment for Dental Problems – oral surgery or dentures	Yes No	Yes No	Yes No	Yes No

70c. AIDS PHARMACEUTICAL ASSISTANCE	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Medication Assistance – financial help to pay for medication not covered by ADAP	Yes No	Yes No	Yes No	Yes No

70d. CASE MANAGEMENT	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Case Manager – someone to help you coordinate your HIV/AIDS care and get benefits	Yes No	Yes No	Yes No	Yes No
Benefits Counseling – help to get benefits you need such as Social Security, ADAP	Yes No	Yes No	Yes No	Yes No
Housing Information – resource to find housing	Yes No	Yes No	Yes No	Yes No

70e. MENTAL HEALTH SERVICES	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Mental Health Counseling - one to one or group counseling	Yes No	Yes No	Yes No	Yes No
Psychiatric Consultation - sessions with a mental health doctor to get a care plan.	Yes No	Yes No	Yes No	Yes No
Crisis Support - crisis mental health support including suicide hotline.	Yes No	Yes No	Yes No	Yes No

70f. SUBSTANCE USE SERVICES	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Substance Abuse Counseling - one to one or group substance abuse counseling	Yes No	Yes No	Yes No	Yes No
Residential Treatment - substance abuse services in a treatment center where you would live	Yes No	Yes No	Yes No	Yes No
Detox Services	Yes No	Yes No	Yes No	Yes No

70g. FOOD SERVICES	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Soft Meals	Yes No	Yes No	Yes No	Yes No
Food Pantry	Yes No	Yes No	Yes No	Yes No
Nutritional Supplements	Yes No	Yes No	Yes No	Yes No
Food Vouchers	Yes No	Yes No	Yes No	Yes No
Home Delivered Meals	Yes No	Yes No	Yes No	Yes No

70h. EMERGENCY ASSISTANCE	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Emergency Financial Assistance for Utilities	Yes No	Yes No	Yes No	Yes No

70i. PSYCHOSOCIAL SUPPORT	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Peer Counseling/Support	Yes No	Yes No	Yes No	Yes No

70j. LEGAL	A	B	C	D
For each service listed below:	Are you aware this service is available to you?	Did you need the service?	Did you receive the service?	IF YOU RECEIVED SERVICE, did it meet your needs?
Legal Assistance	Yes No	Yes No	Yes No	Yes No

71. Below is a list of issues that you may have had when trying to obtain or use HIV/AIDS services. Mark an “X” in the box beside each item to say how big a challenge it has been for you. You may choose from a “very big” challenge to “not a problem.”

“Very Big” = It stopped you from getting the service.

“Medium” = You faced substantial problems but you were eventually able to get the services.

“Very Small” = Caused you minor concern and/or delays in obtaining the service.

“Not a Problem” = You experienced no challenges at all.

	Very Big	Big	Medium	Small	Very Small	No Problem
<i>Example: This survey is difficult to complete.</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not know that a service or treatment was available to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not know where to go to get the service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not know what medical services I needed for my HIV/AIDS.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My physical health has not allowed me to travel to where the service is provided.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My state of mind or ability to deal with the treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Current or recent drug or alcohol use.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was in jail or prison.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have been denied or been afraid to seek services because I was in jail or prison.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear that people would find out I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of privacy by the organization to protect my medical chart.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear that I would be reported to immigration or other authorities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No transportation or access to adequate transportation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The service I need is not available at a time I can get there.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The service is not available in my county (specify your county _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is no on-site child care provided by the agency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of time I had to wait for an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was not able to use my preferred language.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I did not know who to ask for help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Cultural sensitivity of the organization and person providing services to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Discrimination by the organization providing the service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	I did not get along with the people providing services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Person providing services to me did not seem to know enough.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	There was no specialist who could provide the specific care I needed. (Specify specialty _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	The organization did not refer me to the services I needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Lack of support to help me get through the system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Instructions I received to obtain the service or treatment I needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	The rules and regulations for services I needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	There is too much paperwork and/or red tape.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Reduced services due to funding cuts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Lack of health insurance coverage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	I was not eligible for the service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

72. Of all the possible HIV/AIDS services you might have needed and received, which three are the most important to you?

[Interviewer Probe: SHOW LIST OF SERVICES]

1. _____
2. _____
3. _____.

73. Now I am going to read you a list of potential discussions you may have had with an HIV service provider. For each type of provider, please tell me whether or not you have had these discussions.

	Medical Provider (i.e., doctor, physician assistant-PA, nurse practitioner)		Case Manager or Social Worker		Health Educator, Counselor, or Substance use treatment counselor		Peer Counselor		No One/ Not Sure	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Your risk of spreading HIV to someone else	Y	N	Y	N	YN		Y	N	Y	N
Use of condoms to reduce spread of HIV/AIDS	Y	N	Y	N	YN		Y	N	Y	N
The risk that a <u>receptive</u> partner in anal or vaginal sex can infect someone else with HIV/AIDS	Y	N	Y	N	YN		Y	N	Y	N
The risk that an <u>insertive</u> partner in anal or vaginal sex can infect someone else with HIV/AIDS	Y	N	Y	N	YN		Y	N	Y	N
The risk of one person with HIV re-infecting another person with HIV	Y	N	Y	N	YN		Y	N	Y	N
The impact a person's viral load may have on infecting someone else with HIV/AIDS	Y	N	Y	N	YN		Y	N	Y	N
Your choices in telling your HIV status to your sexual and injection drug use partners	Y	N	Y	N	YN		Y	N	Y	N
The risks of combining club or party drug use and sex	Y	N	Y	N	YN		Y	N	Y	N
The impact of Hepatitis C on a person with HIV	Y	N	Y	N	YN		Y	N	Y	N

74. The next questions ask about substance use and how often you have used each of the substances.

Have you EVER used any of the following substances? [INTERVIEWER: READ LIST BELOW]

IF YOU HAVE USED DURING THE PAST YEAR, how often did you use any of the following?

	<u>EVER used</u>		<u>If used in the PAST YEAR</u>			
	<u>No</u>	<u>Yes</u>	<u>Not used in the last year</u>	<u>Used less than once a month</u>	<u>Used at least once a month</u>	<u>Used once a week or more</u>
Alcohol	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Marijuana or hash	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crack/cocaine	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heroin	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crystal meth or methamphetamines	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speedball	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GHB (Gamma Hydroxybutyrate)	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poppers	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ecstasy (X)	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Special K (Ketamine)	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using erectile drugs such as Viagra together with street drugs	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prescription drugs for club or party use (specify) _____	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify) _____	N	Y→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

75. Have you used a needle to inject any street drugs in the last year?

Yes

No

76b. How often have you used a needle exchange service in the past year?

Never

Sometimes

Always

76. Have you used a needle to inject hormones or or steroids in the last year?

Yes

No → Go to Q. 77

77. Where were you born?

United States (mark box and skip to Q. 78)

Mexico

Puerto Rico or other US Territories

Central America

Africa

Caribbean

Other (Specify) _____

76a.How often have you shared needles with someone in the past year?

Never

Sometimes

Always

78. If not born in the United States, what year did you first come to the US? _____

79. [READ ALOUD] Now I am going to read you some statements about your experiences and opinions of how people living with HIV/AIDS feel and how they have been treated. For each statement, please let me know if it ALWAYS, VERY OFTEN, SOMETIMES, ONCE IN AWHILE, OR NEVER happens to you and you believe it is because of your HIV+ status.

	Very Often	Sometimes	Once in awhile	Never	Don't know
a. I have been denied employment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I have been a victim of domestic violence/intimate partner violence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I have been denied services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I have been treated differently by health care staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I have been spoken to harshly by health care staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I have lost jobs when my employers have found out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Health care staff have made me feel ashamed about having HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Health care staff have told me that getting HIV is what I deserved for how I live my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Some people avoided touching me once they knew I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I worry that people who know I have HIV will tell others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. I worry that people might judge me when they learn I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Since learning I have HIV, I feel set apart and isolated from the rest of the world.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. I have lost or been denied housing because of my HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

[READ ALOUD] Before we finish this survey, do you have any other comments about the way you get HIV or AIDS related services? If so, please let me know.