

# PROJECT NASAH

● This survey is for African people with HIV ● It is being carried out by a range of HIV organisations ● The results will be used to develop anti-HIV treatment education services for African people ● The survey is ANONYMOUS - please do not write the respondents name on this form. Please answer honestly. Thank you.

<b>Today's date:</b>
<b>Interviewer's name:</b>
<b>Language used:</b>

## <About you ... >

1. Are you:  male  female

2. What country were you born in? \_\_\_\_\_

### IF BORN OUTSIDE THE UK ASK:

3. How long have you lived in the UK? [ ] year/s

4. Which Local Authority do you live in? \_\_\_\_\_

(e.g. Lambeth, Hackney). If they don't know their local authority, ask the FIRST HALF of their home postcode (e.g. E17) or the name of their area (e.g. Stockwell, Walthamstow)

5. What year were you born in? 19\_\_\_\_year

6. Do you have either a husband/ wife or partner?

- NO  
 YES

7. Do you have any children?

- NO  
 YES ... How many children live with you? [ ]

8. What is your religious affiliation?

- Protestant  
 Anglican  
 Catholic  
 Orthodox  
 Islam (Muslim)  
 None  
 Other - *please say what:* \_\_\_\_\_

9. What is your highest educational qualification?

- I have no educational qualifications  
 O-levels/ GCSEs/ CSEs or equivalent (left school at age 16)  
 A-levels or equivalent (left school at age 18)  
 University degree or higher  
 Other, such as vocational or professional qualifications

- *please say what:* \_\_\_\_\_

**10. Are you:** (TICK ALL THAT APPLY)

- in full-time paid employment
- in part-time paid employment
- Self employed
- Unemployed
- 'signed off' long term sick
- Retired
- on a training scheme / Back-to-Work type activity (Positive Futures etc.)
- Student
- Other - *please say what:* \_\_\_\_\_

**<You and HIV .....>**

**11. When were you diagnosed with HIV?** (\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_) **MM/YY**

**12. Where were you first diagnosed with HIV?**

- in a GUM / STD / HIV clinic
- at your GP (family doctor)
- in hospital (on a ward)
- Ante-natal clinic (during pregnancy)
- Other - *please say where:* \_\_\_\_\_

**13. Since your diagnosis, have you been ill BECAUSE OF HIV (not including treatment side effects)?**

- NO
- YES

**14. Which HIV (GUM) clinic do you usually go to?** \_\_\_\_\_  
(IF THEY DO NOT USE A CLINIC WRITE NONE)

**15. How often do you go to your HIV (GUM) clinic?**

- More than once a month
- Every month
- Every three months
- Every six months
- Less often
- Never

**16. Who knows that you have HIV? (TICK ONCE ON EACH LINE)**

	<b>YES</b>	<b>NO</b>	<b>NOT APPLICABLE</b>	
your partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
your GP (family doctor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
your mother	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
your father	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	<b>ALL</b>	<b>SOME</b>	<b>NONE</b>	<b>NOT APPLICABLE</b>
your children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
your brothers / sisters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
your friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
your work colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
other people you live with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**17. In the last 12 months, have you had any problems (for ANY reason) in relation to:** (TICK ALL THAT APPLY)

	<b>YES</b>	<b>NO</b>	<b>NOT APPLICABLE</b>
Housing and living conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating and drinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household chores and self care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility - ability to get about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Money – getting enough to live on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drugs and alcohol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety and depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-confidence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Immigration status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friendships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Looking after children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledge of anti-HIV treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking anti-HIV treatments regularly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dealing with health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discrimination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Skills, training and job opportunities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## <Using anti-HIV treatments>

**18. Have you EVER taken any anti-HIV treatments (or anti-retroviral therapy)?**

- NO → **GO TO QUESTION 28**  
 YES

**19. Have you EVER experienced any side effects from anti-HIV treatments?**

- NO  
 YES

**20. Are you taking any anti-HIV treatments, AT THE MOMENT?**

- NO → **GO TO QUESTION 28**  
 YES

**21. Do you feel you know enough about the anti-HIV treatments you are taking, AT THE MOMENT?**

- NO  
 YES  
 NOT SURE

**22. AT THE MOMENT, how many times a day do you have to take any kind of anti-HIV treatments?**

- I don't take any medicines at all → **GO TO QUESTION 28**  
 Once a day  
 Twice a day  
 Three times a day  
 Four or more times a day

**23. How do you find taking anti-HIV treatments?**

- EASY
- OK
- DIFFICULT

**24. How many doses of anti-HIV treatments have you missed in the LAST TWO WEEKS?**

- NONE
- ONE or TWO doses
- FIVE or SIX doses
- THREE or FOUR doses
- SEVEN or MORE doses

**25. Do you tell your doctor when you miss doses of anti-HIV treatments?**

- YES
- NO
- SOMETIMES
- I NEVER MISS DOSES

**26. What are the most common reasons for you missing doses of anti-HIV treatments? (TICK ALL THAT APPLY)**

- I just forget sometimes
- I have physical difficulty in taking them (swallowing, pill size etc.)
- Side effects make it difficult (vomiting, sleeping etc.)
- I have no privacy to take them (people around me don't know my status)
- My social life interferes (hard to take them when I am out with friends / family)
- My working life interferes (hard to take them when I am at work)
- Other - ***please say what:*** \_\_\_\_\_

**27a How often do you understand what HIV clinic staff tell you about your anti-HIV treatments?**

- Never
- Usually
- Always

**27b How often do you ask HIV clinic staff questions when you don't understand what they are saying about your anti-HIV treatments?**

- Never
- Usually
- Always

**27c How satisfied are you about the way you and the HIV clinic staff make decisions together, about your anti-HIV treatments?**

- Very satisfied
- Somewhat satisfied
- Not at all satisfied

**28. In the last 12 months, have you had any problems getting access to anti-HIV treatments?**

- NOT NEEDED ANY
- NO
- YES - **if YES, What problems have you had?**

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## <Knowledge of anti-HIV treatments>

**29. In the past 12 months, have you had any problems getting information about anti-HIV treatments?**

- NOT NEEDED ANY  
 NO  
 YES

**30. Overall, are you satisfied with what you know about anti-HIV treatments?**

- NO  
 YES

**31. More specifically, are you satisfied with what you know about:**

(TICK ONCE ON EACH LINE)

	YES	Not Sure	NO
Adherence (taking treatment exactly as prescribed)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of anti-HIV treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CD4	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical trials of anti-HIV treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Illnesses related to HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lipodystrophy (body fat changes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Looking after children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutrition / dietary advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pregnancy and HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Preventing HIV transmission	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resistance to anti-HIV treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side-effects of anti-HIV treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Viral load	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**32. All the following statements about HIV and AIDS are TRUE. For each statement, please indicate whether: you already knew this; you weren't sure about it; you didn't know this already. (TICK ONCE ON EACH LINE)**

	Knew it	Not Sure	Didn't Know
Missing doses of anti-HIV treatments can allow drug resistance to develop	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some anti-HIV treatments cause cholesterol levels to rise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undetectable viral load does not mean that HIV has been eradicated from the body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anti-HIV treatments can stop many pregnant women with HIV passing it to their child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug resistance is an important reason why HIV treatments may fail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anti-HIV treatments prevent HIV from damaging your immune system, and so prevent ill health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A woman with HIV can pass it to her child during breastfeeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At present, combinations of at least three anti-HIV drugs provide the best chance of reducing the amount of HIV in your blood to very low levels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuropathy means damage to the nerves	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**33. Thinking about what you ALREADY know about anti-HIV treatments, which of the following activities have you done in the LAST 12 MONTHS?**

(TICK ONCE ON EACH LINE)

	Done it	NOT done it
READ leaflets and pamphlets	<input type="radio"/>	<input type="radio"/>
READ newsletters and the HIV-positive press	<input type="radio"/>	<input type="radio"/>
READ web-pages / the internet	<input type="radio"/>	<input type="radio"/>
READ medical journals	<input type="radio"/>	<input type="radio"/>
READ mainstream newspapers and magazines	<input type="radio"/>	<input type="radio"/>
TALKED with medical staff like doctors or nurses <i>etc.</i>	<input type="radio"/>	<input type="radio"/>
TALKED with workers from black organisations	<input type="radio"/>	<input type="radio"/>
TALKED with workers from HIV organisations	<input type="radio"/>	<input type="radio"/>
TALKED informally with other people with HIV	<input type="radio"/>	<input type="radio"/>
TALKED with other people with HIV at support groups	<input type="radio"/>	<input type="radio"/>
TALKED with my friends	<input type="radio"/>	<input type="radio"/>
ATTENDED presentations (seminars) from medical staff	<input type="radio"/>	<input type="radio"/>
ATTENDED presentations from other positive people	<input type="radio"/>	<input type="radio"/>

**34. FOR EACH OF THE ACTIVITIES TICKED IN Q.33 (ABOVE) ASK:**

**How IMPORTANT have the following activities been to your learning about anti-HIV treatments?** (TICK ONCE ON EACH LINE)

	Very Imp.	A little	Not at all
READING leaflets and pamphlets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
READING newsletters and the HIV-positive press	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
READING web-pages / the internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
READING medical journals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
READING mainstream newspapers and magazines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TALKING with medical staff like doctors or nurses <i>etc.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TALKING with workers from black organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TALKING with workers from HIV organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TALKING informally with other people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TALKING with other people with HIV at support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TALKING with my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ATTENDED presentations (seminars) from medical staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ATTENDED presentations from other positive people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**IF THEY DO ANY READING (ie. THE FIRST 5 ITEMS IN Q. 33 OR Q. 34) ASK Q. 35.**

**IF THEY DO NOT TICK ANY READING ITEMS GO TO Q. 38.**

**35. How do you usually get hold of the publications you read?**

(TICK ALL THAT APPLY)

- I subscribe to them / they are delivered to my home
- I pick them up at the HIV (GUM) clinic
- I pick them up at a support group / HIV organisation
- from the internet
- from friends
- Other - ***how you get them?*** \_\_\_\_\_

**36. Do you take any publications you read home with you?**

- NO
- YES

**IF NO TO Q. 36 ASK:**

**Why do you not take them home with you?**

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**37. Generally speaking, are you satisfied with the information you READ about anti-HIV treatments?**

- Very satisfied
- Somewhat satisfied
- Not at all satisfied

**IF NOT AT ALL SATISFIED IN Q. 37 ASK:**

**How could written information about anti-HIV treatments be improved?**

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**38. WHO or WHAT has been most helpful to you in finding out about anti-HIV treatments?**

Most important: \_\_\_\_\_

2<sup>nd</sup> most important: \_\_\_\_\_

3<sup>rd</sup> most important: \_\_\_\_\_

## <Finding out more about treatments>

### 39. Would you like to know more about anti-HIV treatments?

- NO → **GO TO QUESTION 42**  
 YES

### 40. How would you like to learn more about anti-HIV treatments in the future? (TICK ALL THAT APPLY)

- by READING leaflets and pamphlets  
 by READING newsletters and the HIV-positive press  
 by READING web-pages / the internet  
 by READING medical journals  
 by READING mainstream newspapers and magazines
- by TALKING with medical staff like doctors or nurses *etc.*  
 by TALKING with workers from black organisations  
 by TALKING with workers from HIV organisations  
 by TALKING informally with other people with HIV  
 by TALKING with other people with HIV at support groups  
 by TALKING with my friends
- by ATTENDING presentations (seminars) from medical staff  
 by ATTENDING presentations (seminars) from other positive people

### 41. What specific area/s would you like to have more information on?

- Adherence (taking treatment exactly as prescribed)  
 Availability of anti-HIV treatments  
 CD4  
 Clinical trials of anti-HIV treatments  
 Illnesses related to HIV  
 Lipodystrophy (body fat changes)  
 Looking after children  
 Nutrition / dietary advice  
 Pregnancy and HIV  
 Preventing HIV transmission  
 Resistance to anti-HIV treatments  
 Side-effects of anti-HIV treatments  
 Viral load  
 Other - ***please say what:*** \_\_\_\_\_

### 42. Is there anything you would like to add that has not been addressed?

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**THANK YOU VERY MUCH FOR TAKING PART  
THIS SURVEY WILL GO TOWARDS IMPROVING  
SERVICES FOR AFRICAN PEOPLE LIVING WITH HIV**