



# ***What do you need?***

*A UK-wide survey about living with HIV*

**Sigma Research has been carrying out community-based research for more than fifteen years. We are the UK's leading social research group specialising in the policy aspects of sexual health and HIV. Sigma Research is based in Vauxhall, South London and is part of the University of Portsmouth.**

**To find out more about Sigma Research visit our website ([www.sigmaresearch.org.uk](http://www.sigmaresearch.org.uk)) or call 020-7820 8022.**

**For more information about this survey go to [www.sigmaresearch.org.uk/projects36.html](http://www.sigmaresearch.org.uk/projects36.html) or call Peter Keogh on 020-7820 8022.**

**This research will be used to help HIV organisations to plan services to meet your needs. The results will be available in early 2008 as a down-loadable file and a free glossy report. To order a copy, call us on 020-7820 8022 or email [Kathie.Jessup@sigmaresearch.org.uk](mailto:Kathie.Jessup@sigmaresearch.org.uk)**

**This research is funded by Terrence Higgins Trust.**

**This booklet has been distributed by:**



### **Please read this information before completing this survey**

- This survey is about living with diagnosed HIV. It is your opportunity to help others understand the needs of people living with HIV.
- This survey is for people who are 16 years of age or older and have diagnosed HIV.
- It will take about twenty minutes to complete.
- Your answers will be anonymous - we do not want your name or address.
- By answering the questions you consent to take part in this research.
- It is up to you if you want to take part in this survey – no one should pressure you to do so, or treat you any differently if you do not. If you are unsure whether you want to take part, talk to someone you trust and do not rush to decide.
- Please read each question carefully and answer all questions honestly.
- Please fill it in just once and return it to the postage-paid address on the back cover.
- **The closing date for the survey is the end of August 2007.**
- Sigma Research complies with the Data Protection Act.  
You can read our confidentiality policy at:  
[www.sigmaresearch.org.uk/secretcy](http://www.sigmaresearch.org.uk/secretcy)

**You can complete the survey online at [www.WhatDoYouNeed.org.uk](http://www.WhatDoYouNeed.org.uk)**

**La version française de cette enquête peut être visité sur le site internet suivant: [www.WhatDoYouNeed.org.uk](http://www.WhatDoYouNeed.org.uk)**



# SOME QUESTIONS ABOUT YOU...

1. Are you...

- Male  
 Female

2. How old are you? \_\_\_\_\_ years

- *This survey is for people aged 16 and over.  
Please do not fill it in if you are under the age of 16.*

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

4. What is your first language? \_\_\_\_\_

5. How long, in total, have you lived in the UK? \_\_\_\_\_ year/s \_\_\_\_\_ months

6. Which local authority do you live in?

\_\_\_\_\_

*Your local authority bills you for council tax.*

*If you don't know your local authority, write in the city / town you live in.*

7. Do you have a husband, wife, civil partner or long-term partner (boyfriend / girlfriend)?

- no  
 yes

8. Do you consider yourself to have a long-term illness other than HIV?

- no  
 yes → Please say what: \_\_\_\_\_

**9. What is your ethnic group?**

Asian or Asian British  Indian  
 Pakistani  
 Bangladeshi  
 any other Asian background  
**→ Please say what:** \_\_\_\_\_

Black or Black British  Caribbean  
 African  
 any other Black background  
**→ Please say what:** \_\_\_\_\_

Mixed  White and Black Caribbean  
 White and Black African  
 White and Asian  
 any other mixed background  
**→ Please say what:** \_\_\_\_\_

White  British  
 Irish  
 any other White background  
**→ Please say what:** \_\_\_\_\_

Other ethnic groups  Chinese  
 any other ethnic group  
**→ Please say what:** \_\_\_\_\_

**10. Apart from paid work, are you responsible for the day-to-day care of:**

- a child / children
- an adult dependent/s (sick, disabled and / or elderly person)
- neither of these

**11. What are your current living arrangements? (tick all that apply)**

- I live alone
- I live with a partner
- I live with a child / children I am responsible for
- I live with my parents / step parents
- I live with other family members → **Please specify:** \_\_\_\_\_
- I live with friends
- I live with housemates or people I share with
- I live in temporary accommodation
- I am in prison
- I live in a detention centre
- I am homeless

**12. What is the highest level of education that you have achieved?**

- None
- Primary / Elementary School
- Secondary / High School
- University / College
- Other → **Please specify:** \_\_\_\_\_

**13. What religion do you currently practice?**

- No religion
- Christian → **Which denomination?** \_\_\_\_\_
- Islam
- Buddhism
- African traditional religion → **Please specify:** \_\_\_\_\_
- Judaism
- Hinduism
- Sikhism
- Other religion → **Please specify:** \_\_\_\_\_

**14. Are you:**

- Heterosexual (straight)
- Gay
- Lesbian
- Bisexual
- Other → Please specify: \_\_\_\_\_

**15. Are you a Trans-person? (Transexual / Transgender – someone who has changed or intends to change their biological sex)**

- no
- yes → How do you describe yourself? \_\_\_\_\_

**16. Do you have haemophilia (a blood disorder that impairs the body's ability to control bleeding)?**

- no
- yes

**17. Have you ever injected drugs (not including any prescribed by your doctor)?**

- no → Please go to question 18
- yes → Have you injected drugs in the last 12 months?
  - no
  - yes

**18. Which of these best describes your current situation? (tick as many as apply)**

- Full-time education
- Part-time education
- on a training scheme / Back-to-Work type activity (Positive Futures etc.)
- Full-time employment
- Part-time employment
- Casual / cash-in-hand employment
- Carer / homemaker
- Not in employment and registered for benefits
- Not in employment and not registered for benefits
- Unable to work (long-term illness / disability / medically retired)
- Not allowed to work (immigration reasons)
- Retired
- Other → Please specify: \_\_\_\_\_

**19. What is the gross income (before any deductions for Income Tax and National Insurance contributions) that you receive from all sources including welfare benefits, NASS payments or pensions?**

- |   |    |                          |
|---|----|--------------------------|
| <input type="checkbox"/> Less than £96 per week | or | Less than £5000 per year |
| <input type="checkbox"/> £96 - £192 per week    | or | £5000 - £9999 per year   |
| <input type="checkbox"/> £193 - £288 per week   | or | 10000 – £14999 per year  |
| <input type="checkbox"/> £289 - £385 per week   | or | £15000 – £19999 per year |
| <input type="checkbox"/> £386 - £481 per week   | or | £20000 – £24999 per year |
| <input type="checkbox"/> £482 - £577 per week   | or | £25000 - £29999 per year |
| <input type="checkbox"/> £578 - £673 per week   | or | £30000 – £34999 per year |
| <input type="checkbox"/> £674 - £769 per week   | or | £35000 – £39999 per year |
| <input type="checkbox"/> £770 or more per week  | or | £40000 or more per year  |

**20. Thinking about the last 3 months, have you used the Internet in any of the following places? (tick all that apply)**

- at home
- at another person's home
- a place of work
- a place of education
- a public library
- a government office, town hall, government agency
- an Internet café or shop
- a community or voluntary organisation
- a post office
- other public place → **Please specify:** \_\_\_\_\_
- none of these



## HIV INFECTION AND TREATMENTS (ARVs, HAART)

21. When were you first diagnosed with HIV? \_\_\_\_\_ month \_\_\_\_\_ year

→ This survey is for people who have ever had a positive HIV test. Please do not fill it in if you have not had a positive HIV test.

22. Where were you first diagnosed with HIV?

- in a GUM / STD / HIV clinic
- at your GP (family doctor)
- at a community testing centre (eg fasTest)
- in hospital (on a ward)
- at an ante-natal clinic (during pregnancy)
- at a private clinic
- other → Please say where: \_\_\_\_\_

23. Who knows that you have HIV? (tick one on each line)

	YES	NO	NOT APPLICABLE
your partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your mother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your father	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your GP (doctor)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	ALL	SOME	NONE	NOT APPLICABLE
your children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your brothers / sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
your work colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
other people you live with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**24. In the last 12 months, have you had any problems getting access to anti-HIV treatments (ARVs, HAART)?**

- not needed any
- no
- yes → **What problems have you had?**

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**25. Have you ever taken anti-HIV treatments?**

- no → *Please go to SECTION A (page 10)*
- yes

**26. Are you currently taking any anti-HIV treatments?**

- no and I am not currently thinking of starting → *Please go to SECTION A*
- no, but I am thinking of starting → *Please go to SECTION A (page 10)*
- yes

**27. In the past 12 months, have you had any problems with your anti-HIV treatments?**

- no → *Please go to question 29*
- yes

**28. What problems have you had with your anti-HIV treatments?** (tick all that apply)

- missed doses because of physical health problems
- missed doses because of mental health problems (eg depression)
- problems with medication side effects (eg vomiting, sleeping etc)
- I just forget to take them sometimes
- sometimes I can't face taking them
- 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)
- my doctor and I don't always agree on the most appropriate monitoring
- my doctor and I don't always agree on appropriate treatments
- other → **Please say what:** \_\_\_\_\_

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

- none
- one or two doses
- three or four doses
- five or six doses
- seven or more doses

# A. IMMIGRATION / ASYLUM

**A1. In the past 12 months, have you had any problems or difficulties with immigration or asylum services in the UK?**

- no → *Please go to section B (page 12)*
- yes

**A2. What problems have you had?**

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**A3. In the past 12 months, have you had any help with these immigration problems?**

- no → *Please go to question A5*
- yes

**A4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> an immigration advisory service |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)   |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic             |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services   |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor)  |
| <input type="checkbox"/> other → <b>say who:</b> _____ | <input type="checkbox"/> a private immigration lawyer    |

**A5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question A8*

**A6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question A8*
- yes
- don't know

**A7. Realistically, what help do you think would make a difference to your immigration / asylum problems? (give one example)**

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**A8. Currently, how do you feel about your problems with immigration / asylum services in the UK?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# B. HOUSING

**B1. In the past 12 months, have you had any problems with your housing?**

- no → *Please go to question B8*
- yes

**B2. What problems have you had?** (tick all that apply)

- unsuitable accommodation
- financial / benefits problems
- homeless / in temporary accommodation
- problems with the council / housing association
- problems with NASS or your asylum team
- problems with your private landlord
- problems with neighbours / other residents
- other → **Please say what:** \_\_\_\_\_

**B3. In the past 12 months, have you had any help with these housing problems?**

- no → *Please go to question B5*
- yes

**B4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> a housing association          |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> other → <b>say who:</b> _____ | <input type="checkbox"/> a general charity              |

**B5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question B8*

**B6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question B8*
- yes
- don't know

**B7. Realistically, what help do you think would make a difference to your housing difficulties** (give one example)

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**B8. Currently, how do you feel about your housing and living conditions?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# C. EATING

**C1. In the past 12 months, have you had any problems with your appetite or your ability to eat and drink?**

- no → *Please go to question C8*
- yes, with my appetite
- yes, with my (physical) ability to eat

**C2. What problems have you had? (tick all that apply)**

- physical health problems (eg problems with mouth / throat or digestion, lack of energy to cook or eat, loss of appetite or taste)
- mental health problems (eg depression, anorexia, bulimia)
- problems with medications (eg nausea, vomiting, diarrhoea, weight loss or weight gain)
- financial problems (not enough money to eat well)
- difficulty accessing specialist food (eg halal food, matoke, maize meal etc)
- other → **Please say what:** \_\_\_\_\_

**C3. In the past 12 months, have you had any help with these eating problems?**

- no → *Please go to question C5*
- yes

**C4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> a nutritionist or dietician    |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> other → <b>say who:</b> _____ | <input type="checkbox"/> a general charity              |



**C5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question C8*

**C6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question C8*
- yes
- don't know

**C7. Realistically, what help do you think would make a difference to your problems with eating and drinking? (give one example)**

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**C8. Currently, how do you feel about your appetite and ability to eat and drink?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# D. SLEEP

## D1. In the past 12 months, have you had any problems sleeping?

- no → *Please go to question D8*
- yes

## D2. What has caused these problems? (tick all that apply)

- physical health problems (eg pain, night sweats, frequent trips to the toilet)
- mental health problems (eg worry, depression, inability to relax)
- problems with medications (eg vivid dreams, night sweats)
- outside noise or disturbance
- other → **Please say what:** \_\_\_\_\_

## D3. In the past 12 months, have you had any help with these sleep problems?

- no → *Please go to question D5*
- yes

## D4. Who (or what) has helped you in the last 12 months or is helping you now?

(tick all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse                    | <input type="checkbox"/> a sleep clinic                 |
| <input type="checkbox"/> my children                            | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents                             | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family                           | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends                             | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> complementary therapies                | <input type="checkbox"/> a general charity              |
| <input type="checkbox"/> alcohol or other (non-prescribed) drug | <input type="checkbox"/> prescribed medications         |
| <input type="checkbox"/> other → <b>say who:</b> _____          |   |

**D5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question D8*

**D6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question D8*
- yes
- don't know

**D7. Realistically, what help do you think would make a difference with your sleep problems? (give one example)**

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**D8. Currently, how do you feel about your ability to sleep as and when you want to?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# E. HOUSE-WORK AND LOOKING AFTER YOURSELF

**E1. In the past 12 months, have you had any problems doing household chores (such as cooking, cleaning) or looking after yourself (such as washing, dressing etc)?**

- no → Please go to question E8
- yes

**E2. What problems have you had? (tick all that apply)**

- physical health problems (eg lack of energy, mobility or physical strength, pain, balance problems)
- mental health problems (eg lack of motivation, depression, anxiety)
- problems with medications (eg neuropathy)
- other → Please say what: \_\_\_\_\_

**E3. In the past 12 months, have you had any help with these problems?**

- no → Please go to question E5
- yes

**E4. Who (or what) has helped you in the last 12 months or is helping you now? (tick all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse    | <input type="checkbox"/> a private home-help / cleaner  |
| <input type="checkbox"/> my children            | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents             | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family           | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends             | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> other → say who: _____ | <input type="checkbox"/> a general charity              |

**E5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question E8*

**E6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question E8*
- yes
- don't know

**E7. Realistically, what help do you think would make a difference to your problems doing household chores? (give one example)**

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**E8. Currently, how do you feel about your ability to do household chores and / or look after yourself?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# F. MOBILITY – GETTING ABOUT

**F1. In the past 12 months, have you had any problems getting around locally (to hospital, the shops, services, or to see friends etc)?**

- no → Please go to question F8
- yes

**F2. What has caused these problems? (tick all that apply)**

- physical health problems (eg lack of energy, mobility or physical strength, pain, cognitive or balance impairments, sight problems)
- mental health problems (eg lack of motivation, depression, anxiety)
- problems with medications (eg neuropathy)
- poor public transport
- lack of money
- other → Please say what: \_\_\_\_\_

**F3. In the past 12 months, have you had any help with these mobility problems?**

- no → Please go to question F5
- yes

**F4. Who (or what) has helped you in the last 12 months or is helping you now?**

(tick all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse    | <input type="checkbox"/> mobility transport services    |
| <input type="checkbox"/> my children            | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents             | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family           | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends             | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> other → say who: _____ | <input type="checkbox"/> a general charity              |

**F5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question F8*

**F6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question F8*
- yes
- don't know

**F7. Realistically, what help do you think would make a difference to your mobility problems? (give one example)**

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**F8. Currently, how do you feel about your ability to get around locally?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# G. GETTING ENOUGH MONEY (OR OTHER BENEFITS) TO LIVE ON

Please answer these questions even if you live partly or wholly on indirect benefits (such as hostel accommodation, NASS payments or food vouchers) or if you receive payment-in-kind for your work or services.

**G1. In the past 12 months, have you had any problems getting enough money (or other benefits) to live on?**

- no → *Please go to question G8*
- yes

**G2. In that last year have you had difficulties paying for or obtaining:** (tick all that apply)

- accommodation
- electricity, gas, water, phone
- food
- day-to-day travel needs
- adequate clothing
- additional therapies or supplements
- furniture or appliances
- household repairs
- the cost of moving or setting up home
- education or training
- other → **Please say what:** \_\_\_\_\_

**G3. In the past 12 months, have you had any help with these money problems?**

- no → *Please go to question G5*
- yes



**G4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> my partner / spouse    | <input type="checkbox"/> specialist debt / finance service |
| <input type="checkbox"/> my children            | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents             | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family           | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends             | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> other → say who: _____ | <input type="checkbox"/> a general charity                 |

**G5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question G8*

**G6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question G8*
- yes
- don't know

**G7. Realistically, what help do you think would make a difference to your money problems?** (give one example)

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**G8. Currently, how do you feel about the money you get to live on?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# H. MANAGING ANXIETY AND DEPRESSION

**H1. In the past 12 months, have you had any problems with anxiety or depression?**

- no → *Please go to question H9*
- yes

**H2. What do you think has caused your anxiety / depression?**

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**H3. In the past 12 months, have you done any of the following:**

- made life changes (eg diet, exercise) to help with anxiety or depression
- sought counselling or psychological help for anxiety or depression
- sought alternative therapies for anxiety or depression
- taken prescribed medications for anxiety or depression
- been hospitalised for anxiety or depression
- been sectioned for anxiety or depression
- other → **Please say what:** \_\_\_\_\_

**H4. In the past 12 months have you had any help with these problems?**

- no → *Please go to question H6*
- yes

**H5. Who (or what) has helped you in the last 12 months or is helping you now?**

(tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> my partner / spouse               | <input type="checkbox"/> community mental health service |
| <input type="checkbox"/> my children                       | <input type="checkbox"/> my parents                      |
| <input type="checkbox"/> other family                      | <input type="checkbox"/> an HIV organisation (charity)   |
| <input type="checkbox"/> my friends                        | <input type="checkbox"/> my HIV (GUM) clinic             |
| <input type="checkbox"/> counselling or psychology service | <input type="checkbox"/> the council / social services   |
| <input type="checkbox"/> my GP practice (family doctor)    | <input type="checkbox"/> a general charity               |
| <input type="checkbox"/> other → <b>say who:</b> _____     | <input type="checkbox"/> prescribed medications          |

**H6. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question H9*

**H7. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question H9*
- yes
- don't know

**H8. Realistically, what help do you think would make a difference to your problems with anxiety / depression? (give one example)**

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**H9. Currently, how do you feel about your ability to cope with anxiety or depression (with any help you are getting)?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# J. LOOKING AFTER CHILDREN

If you are NOT responsible for day-to-day care of a child / children PLEASE GO TO SECTION K (PAGE 28).

**J1. In the past 12 months, have you had any problems or difficulties looking after children (NOT including any childcare you get paid for)?**

no → Please go to question J8

yes

**J2. What problems have you had?**

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**J3. In the past 12 months, have you had any help with these problems?**

no → Please go to question J5

yes

**J4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

my partner / spouse

my children

my parents

other family

my friends

other → say who: \_\_\_\_\_

children's charity

an HIV organisation (charity)

my HIV (GUM) clinic

the council / social services

my GP practice (family doctor)

a general charity

**J5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question J8*

**J6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question J8*
- yes
- don't know

**J7. Realistically, what help do you think would make a difference to your problems with looking after children? (give one example)**

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**J8. Currently, how do you feel about your ability to look after your children (with any help you are getting)?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are
- Not applicable

# K. RELATIONSHIPS WITH PARTNERS

(husband, wife, civil partner, long-term partner)

If you have not had a regular partner in the last 12 months PLEASE GO TO SECTION L (page 30).

**K1. In the past 12 months, have you had any problems or difficulties with your partner?**

- no → Please go to question K8
- yes

**K2. What problems have you had?**

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**K3. In the past 12 months, have you had any help with these problems?**

- no → Please go to question K5
- yes

**K4. Who (or what) has helped you in the last 12 months or is helping you now?**

(tick all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> my partner / spouse    | <input type="checkbox"/> counselling or psychology service |
| <input type="checkbox"/> my children            | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents             | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family           | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends             | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> other → say who: _____ | <input type="checkbox"/> a general charity                 |

**K5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question K8*

**K6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question K8*
- yes
- don't know

**K7. Realistically, what help do you think would make a difference to your problems with your partner? (give one example)**

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**K8. Currently, how do you feel about your relationship with your partner?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# L. RELATIONSHIPS WITH YOUR FAMILY

**L1. In the past 12 months, have you had any problems in your relationships with your family?**

- no → *Please go to question L8*
- yes

**L2. What problems have you had? (tick all that apply)**

- Complete rejection by family members
- Bad attitude / poor response of family members concerning HIV
- Anxiety about disclosing your HIV status to family members
- Poor communication between you and family members
- Difficulty responding to your family member's needs or demands
- Family members have breached your trust in them
- I miss my family (I do not live near them).
- other → **Please say what:** \_\_\_\_\_

**L3. In the past 12 months, have you had any help with these problems?**

- no → *Please go to question L5*
- yes

**L4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> counselling or psychology service |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> other → <b>say who:</b> _____ | <input type="checkbox"/> a general charity                 |



**L5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question L8*

**L6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question L8*
- yes
- don't know

**L7. Realistically, what help do you think would make a difference with your family problems? (give one example)**

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**L8. Currently, how do you feel about your relationship with your family?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# M. FRIENDSHIPS

**M1. In the past 12 months, have you had any problems with your current friendships or with making new friends?**

- no → *Please go to question M8*
- yes

**M2. What problems have you had?** (tick all that apply)

- I have no friends
- Being isolated
- Complete breakdown / loss of friendships
- Bad attitude / poor response of friends concerning HIV
- Anxiety about disclosing your HIV status to friends
- Poor communication between you and your friends
- Difficulty making new friends
- Difficulty responding to your friend's needs or demands
- Friend / s have breached your trust in them
- other → **Please say what:** \_\_\_\_\_

**M3. In the past 12 months, have you had any help with these problems?**

- no → *Please go to question M5*
- yes

**M4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> counselling or psychology service |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> other → <b>say who:</b> _____ | <input type="checkbox"/> a general charity                 |

**M5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question M8*

**M6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question M8*
- yes
- don't know

**M7. Realistically, what help do you think would make a difference to your problems with your friendships? (give one example)**

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**M8. Currently, how do you feel about your friendships?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# N. SEX

## N1. In the past 12 months, have you had any problems with your sex life?

- no → Please go to question N8
- yes

## N2. What problems have you had? (tick all that apply)

- too little or no sex
- problems with your penis, vagina or anus (eg erection problems, pain)
- loss of libido
- too much sex
- worries about disclosing HIV status to sexual partner / s
- worries about being prosecuted if HIV is passed on
- fear of rejection from potential sexual partners
- poor self image / low self confidence
- worries about passing HIV on to sexual partner / s
- treatment side effects
- other → Please say what: \_\_\_\_\_

## N3. In the past 12 months, have you had any help with these problems?

- no → Please go to question N5
- yes

## N4. Who (or what) has helped you in the last 12 months or is helping you now? (tick all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> my partner / spouse    | <input type="checkbox"/> counselling or psychology service |
| <input type="checkbox"/> my children            | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents             | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family           | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends             | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> other → say who: _____ | <input type="checkbox"/> a general charity                 |

**N5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question N8*

**N6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question N8*
- yes
- don't know

**N7. Realistically, what help do you think would make a difference to your problems with sex? (give one example)**

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**N8. Currently, how do you feel about your sex life?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# O. DRUGS OR ALCOHOL

**O1. In the last 12 months, have you felt you had a problem with any of the following drugs?** (tick all that apply)

- Alcohol
- Amphetamines (speed, uppers)
- Amyl nitrite (poppers)
- Cannabis (marijuana, grass, spliff)
- Crystal methamphetamine (tina)
- Cocaine
- Crack (rock, stones)
- Ecstasy ('E')
- GHB / GBH
- Heroin (smack, 'H', brown)
- Ketamine ('K', special K)
- Khat
- LSD (acid)
- Magic mushrooms
- Tranquillizers (eg. Temazepam)
  
- None of the above → Please go to SECTION P (page 38)

**O2. What problems have you experienced in the last 12 months?**

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**O3. In the past 12 months, have you had any help with these problems?**

- no → Please go to question O5
- yes

**04. Who (or what) has helped you in the last 12 months or is helping you now?**

(tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> counselling or psychology service |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> a general charity             | <input type="checkbox"/> an alcohol / drugs organisation   |
| <input type="checkbox"/> other → <b>say who:</b> _____ |  |

**05. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question 08*

**06. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question 08*
- yes
- don't know

**07. Realistically, what help do you think would make a difference to your problems?**  
(give one example)

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**08. Currently, how do you feel about your drug / alcohol use?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

## P. SELF-ESTEEM (SELF-BELIEF, SELF-CONFIDENCE)

**P1. In the past 12 months, have you had any problems with your self-esteem?**

- no → *Please go to question P8*
- yes

**P2. What do you think has caused your problems with your self-esteem?**

- changes to your appearance or body
- anxiety / depression
- isolation / exclusion
- problems at work
- relationship problems
- sexual dysfunction
- anxieties about disclosing your HIV status
- worries about the future
- other → **Please say what:** \_\_\_\_\_

**P3. In the past 12 months, have you had any help with these problems?**

- no → *Please go to question P5*
- yes

**P4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> counselling or psychology service |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)     |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic               |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services     |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor)    |
| <input type="checkbox"/> a general charity             | <input type="checkbox"/> surgery (eg New-Fill)             |
| <input type="checkbox"/> other → <b>say who:</b> _____ |  |



**P5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question P8*

**P6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question P8*
- yes
- don't know

**P7. Realistically, what help do you think would make a difference to your problems with self-esteem? (give one example)**

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**P8. Currently, how do you feel about your self-esteem?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# Q. TRAINING AND SKILLS

**Q1. In the past 12 months, have you considered learning new skills or retraining?**

- no → *Please go to question Q8*
- yes

**Q2. What skills have you considered learning or improving?**

- computing / IT
- languages
- management / business admin
- complementary therapies
- counselling
- art and design
- teaching
- nursing
- other → **Please say what:** \_\_\_\_\_

**Q3. In the past 12 months, have you had any training or other help learning new skills?**

- no → *Please go to question Q5*
- yes

**Q4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> a 'back to work' service       |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> other → <b>say who:</b> _____ | <input type="checkbox"/> a general charity              |

**Q5. Compared to a year ago, has your interest in learning new skills / retraining increased, decreased or gone away?**

- no change
- decreased
- increased
- gone away → *Please go to question Q8*

**Q6. With more help or support, do you think you could further improve your skills?**

- no → *Please go to question Q8*
- yes
- don't know

**Q7. Realistically, what help do you think would enable you to improve your skills?**  
(give one example)

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**Q8. Currently, how do you feel about your ability to access training / skills development?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# R. PROBLEMS WITH WORK

**R1. In the past 12 months, have you experienced any problems with getting a job or advancing in your current job?**

- no → *Please go to question R8*
- yes

**R2. What problems have you experienced?**

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**R3. In the past 12 months, have you had any help with these problems?**

- no → *Please go to question R5*
- yes

**R4. Who (or what) has helped you in the last 12 months or is helping you now?**  
(tick all that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> my partner / spouse           | <input type="checkbox"/> a 'back to work' service       |
| <input type="checkbox"/> my children                   | <input type="checkbox"/> an HIV organisation (charity)  |
| <input type="checkbox"/> my parents                    | <input type="checkbox"/> my HIV (GUM) clinic            |
| <input type="checkbox"/> other family                  | <input type="checkbox"/> the council / social services  |
| <input type="checkbox"/> my friends                    | <input type="checkbox"/> my GP practice (family doctor) |
| <input type="checkbox"/> a solicitor / lawyer          | <input type="checkbox"/> a general charity              |
| <input type="checkbox"/> other → <b>say who:</b> _____ |   |

**R5. Compared to a year ago, have these problems got better, worse or gone away?**

- no change
- better
- worse
- been solved or gone away → *Please go to question R8*

**R6. With more help or support, do you think you could reduce, or overcome these problems?**

- no → *Please go to question R8*
- yes
- don't know

**R7. Realistically, what help do you think would make a difference to your problems with getting a new job or advancing in your current job? (give one example)**

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**R8. Currently, how do you feel about your opportunities in your job / on the job market?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# S. DISCRIMINATION

**S1. In the past 12 months, have you experienced discrimination from FAMILY MEMBERS?**

- no → *Please go to question S4*
- yes

**S2. What discrimination have you experienced from family members?**

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**S3. On what basis do you think your family discriminated against you?**

(tick all that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> HIV status                      | <input type="checkbox"/> physical appearance            |
| <input type="checkbox"/> sexuality                       | <input type="checkbox"/> ethnicity                      |
| <input type="checkbox"/> gender                          | <input type="checkbox"/> disability                     |
| <input type="checkbox"/> age                             | <input type="checkbox"/> drug use                       |
| <input type="checkbox"/> being a migrant / asylum seeker | <input type="checkbox"/> other → <b>say what:</b> _____ |

**S4. In the past 12 months, have you experienced discrimination from MEMBERS OF YOUR COMMUNITY?**

- no → *Please go to question S7*
- yes

**S5. What discrimination have you experienced from members of your community?**

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**S6. On what basis do you think that members of your community discriminated against you?** (tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> HIV status                      | <input type="checkbox"/> physical appearance     |
| <input type="checkbox"/> sexuality                       | <input type="checkbox"/> ethnicity               |
| <input type="checkbox"/> gender                          | <input type="checkbox"/> disability              |
| <input type="checkbox"/> age                             | <input type="checkbox"/> drug use                |
| <input type="checkbox"/> being a migrant / asylum seeker | <input type="checkbox"/> other → say what: _____ |

**S7. In the past 12 months, have you experienced discrimination from DOCTORS OR OTHER HEALTH OR CARE PROFESSIONALS?**

- no → Please go to SECTION T (page 46)
- yes

**S8. What discrimination have you experienced from doctors or other health care professionals?**

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**S9. On what basis do you think that doctors or other healthcare professionals discriminated against you?** (tick all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> HIV status                      | <input type="checkbox"/> physical appearance     |
| <input type="checkbox"/> sexuality                       | <input type="checkbox"/> ethnicity               |
| <input type="checkbox"/> gender                          | <input type="checkbox"/> disability              |
| <input type="checkbox"/> age                             | <input type="checkbox"/> drug use                |
| <input type="checkbox"/> being a migrant / asylum seeker | <input type="checkbox"/> other → say what: _____ |

# T. GETTING INFORMATION

**T1. In the past 12 months, have you had any problems accessing information about living well with HIV?**

- no → *Please go to question T3*
- yes

**T2. What problems have you experienced?**

- I don't know where to start looking for information
- It's hard to find the information I need
- the information I have found is poor quality
- the information I have found is too complex
- the professionals I have contacted don't communicate properly with me
- other → **Please say what:** \_\_\_\_\_

**T3. Would you like to know more about living well with HIV?**

- no → *Please go to question T5*
- yes



**T4. How would you like to learn more about these topics 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 (charities)
- by TALKING with workers from Gay organisations (charities)
- by TALKING with workers from HIV organisations (charities)
- by TALKING with workers from haemophilia organisations (charities)
- by TALKING with workers from drugs support organisations (charities)
- 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
- by ATTENDING groups and courses run by HIV organisations (charities)

**T5. Currently, how do you feel about your ability to access information?**

- I'm very happy with things as they are
- I'm fairly happy with things as they are
- I'm fairly unhappy with things as they are
- I'm very unhappy with things as they are

# U. AND FINALLY ...

**U1. Please tell us about any other needs that you feel you have, which have not been addressed in this questionnaire.**

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**U2. Have you filled in this survey already this summer?**

- No
- Yes

**U3. Do you have any comments or suggestions about this survey?**

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**Many thanks for taking part.  
Your answers are completely anonymous.  
Please remember to seal and post this booklet.**

The results of this survey will be available in early 2008 at  
[www.sigmaresearch.org.uk](http://www.sigmaresearch.org.uk) where you  
can also find the results from similar surveys.

Sigma Research is running two other surveys this summer.

If you are African and living in England please take part in [www.bass-line.org.uk](http://www.bass-line.org.uk)

If you are a man who has sex with men please take part in [www.vitalstatistics.org.uk](http://www.vitalstatistics.org.uk)