WHAT DO YOU NEED?

A UK-wide survey about living with HIV
Sigma Research has been carrying out community-based HIV research for more than ten years. We are the UK’s leading social research group specialising in the policy aspects of HIV and sexual health.

Sigma Research is based in Brixton, South London and is a charity by affiliation to the University of Portsmouth. If you would like to know more about our work please visit our website at www.sigmaresearch.org.uk or write to Michael Stephens using the address on the back cover of this booklet.

*What do you need* is jointly funded by CRUSAID and Camden & Islington Health Authority.

This booklet has been distributed by:
This survey is about living with HIV. This questionnaire is being distributed all over the U.K. in HIV newsletters and papers and by HIV charities, clinics and other service providers. The findings will be used to help HIV organisations to plan services to meet your needs.

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. The survey is anonymous: we don’t want your name or address, and no one outside Sigma will ever see your completed questionnaire. Please answer all questions honestly.

What do you need? is a UK-wide survey happening throughout the summer of 2001. It is your opportunity to help others understand the needs of people living with HIV.

The questionnaire will take 15-20 minutes to complete. Please fill it in just once and return it to the postage-paid address on the back cover.

The closing date for returns is 31st August 2001.

The results of this survey will be posted on our website by 30th November 2001. The full report will be available as a downloadable file and as a free hard-copy glossy report. If you would like to register your interest in receiving these you can do so on the website, or by emailing michael@sigmaresearch.org.uk or by telephoning Michael or Dale (020-7737 6223) and asking to receive What do you need? when it comes out.

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www.sigmaresearch.org.uk

We comply with the data protection act.
SOME QUESTIONS ABOUT YOU…

1. Are you:
   □ male
   □ female

2. How old are you? _______ years old

3. What is your ethnic group?
   Asian / Asian British
   □ Indian
   □ Pakistani
   □ Other, specify: ______________________

   Black / Black British
   □ Caribbean
   □ African
   □ Other, specify: ______________________

   Chinese
   □

   White
   □ Irish
   □ British
   □ Other, specify: ______________________

   Mixed (ethnic group)
   □ specify: ____________________________

   Other
   □ specify: ____________________________

4. Which Local Authority do you live in? _______________________________________
   (who sends your household the Council Tax bill?)
   If you don’t know your local authority, write in the first half of your HOME POSTCODE or the
   name of the town or city you live in. If you live outside the UK, write in your country of residence.

5. Are you Registered Disabled?
   □ no
   □ yes

6. Do you have a partner, husband or wife?
   □ no
   □ yes

7. Do you have any children?
   □ no
   □ yes ➔ Please list their ages: _________________________________ years old
8. **What are your current living arrangements?** (tick all that apply)

- [ ] I live alone
- [ ] I live with a partner
- [ ] I live with children
- [ ] I live with my parents
- [ ] I live with friends
- [ ] I live with other tenants
- [ ] I am in temporary accommodation
- [ ] I am homeless

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 describe:**

10. **Are you:**

- [ ] Straight / heterosexual
- [ ] Gay
- [ ] Lesbian
- [ ] Bisexual
- [ ] Other ➔ **please describe:**

11. **Do you have haemophilia?**

- [ ] no
- [ ] yes

12. **Have you ever injected drugs (such as heroin)?**

- [ ] no
- [ ] yes ➔ **Have you injected drugs in the last 12 months?**

  - [ ] no
  - [ ] yes

13. **Do you have any problems associated with immigration to the UK?**

- [ ] no
- [ ] yes ➔ **please describe your problems**
14. Have you done any voluntary work in the last year?

☐ no
☐ yes ➔ who for? ______________________________

15. Are you: (tick all that apply)

☐ in full-time paid employment ➔ GO TO question 17
☐ in part-time paid employment ➔ GO TO question 17
☐ self employed ➔ GO TO question 17
☐ unemployed
☐ ‘signed off’ long term sick
☐ retired
☐ student
☐ other ➔ please describe: ______________________________

16. Are you interested in getting paid work?

☐ no
☐ yes

17. Which of the following do you regularly receive? (tick all that apply)

☐ a salary/ wage
☐ other earnings
☐ unemployment benefits / income support
☐ sickness or disability benefits
☐ asylum seekers allowance
☐ social services payments
☐ free travel passes or tokens
☐ supermarket vouchers
☐ a pension
☐ money from partner or family
☐ other income ➔ please describe: ______________________________

NOW A FEW QUESTIONS ABOUT HIV INFECTION

18. When were you diagnosed with HIV? ___________ month ___________ year

19. Have you ever been ill because of HIV (not including treatment side effects)?

☐ no
☐ yes
20. Have you ever taken anti-HIV treatments?
   □ no  ➔ GO TO question 24
   □ yes

21. When did you first start taking any anti-HIV treatments? _______ month _______ year

22. Have you experienced any side effects from anti-HIV treatments?
   □ no
   □ yes

23. Currently, are you taking any anti-HIV treatments?
   □ no  ➔ Why did you stop taking anti-HIV treatments? _________________________________
   □ yes

24. Currently, are you taking medicines other than anti-HIV treatments?
   □ no
   □ yes

25. How many times a day do you have to take any kind of medicine?
   □ I don't take any medicines at all  ➔ GO TO question 27
   □ once
   □ twice
   □ three times
   □ four times
   □ five times
   □ six or more times

26. How often do you miss a dose of medicine?
   □ about once a day
   □ about once every two days
   □ about once a week
   □ about once a fortnight
   □ about once a month
   □ less often
   □ I never miss a dose

27. Currently, are you using any complementary or alternative therapies?
   □ no
   □ yes  ➔ please name them

___________________________________________________________________________________
___________________________________________________________________________________

WHAT DO YOU NEED? 5
A. HOUSING

A1. In the past 12 months, have you had any problems with your housing?

☐ no ➔ GO TO question A9
☐ yes

A2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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)

☐ my partner / spouse  ☐ an HIV organisation
☐ my children  ☐ my HIV (GUM) clinic
☐ my parents  ☐ the council / social services
☐ other family  ☐ my GP practice (family doctor)
☐ my friends  ☐ an advice or counselling agency
☐ a self-help group  ☐ a telephone helpline
☐ other ➔ please say who or what

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

☐ No change
☐ Better ➔ Why?

☐ Worse ➔ Why?

☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question A9
A6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question A9
☐ yes
☐ don’t know

A7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

A8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________

A9. 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.
B. EATING/DRINKING

B1. In the past 12 months, have you had any problems with your appetite or your ability to eat and drink?
- no ➔ GO TO question B9
- yes with my appetite
- yes with my (physical) ability to eat

B2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

B3. In the past 12 months, have you had any help with these problems?
- no ➔ 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)
- my partner / spouse
- my children
- my parents
- other family
- my friends
- a self-help group
- other ➔ please say who or what

B5. Compared to a year ago, have these problems got better, worse or gone away?
- No change
- Better ➔ Why?
- Worse ➔ Why?
- Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question B9
B6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no ➔ GO TO question B9
☐ yes
☐ don't know

B7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

B8. Why have you not got this help at the moment? (tick all that apply)

☐ I'm getting all the help that is available
☐ It's not available
☐ I don't really need it
☐ I haven't asked for it
☐ I can manage without it
☐ I don't know how to get it
☐ I can't afford it
☐ I don't want to use it ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other ➔ please say why not?

___________________________________________________________________________________

B9. 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.
C. SLEEP

C1. In the past 12 months, have you had any problems sleeping?

☐ no  ➔ GO TO question C9
☐ yes

C2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no  ➔ 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)

☐ my partner / spouse  ☐ an HIV organisation
☐ my children  ☐ my HIV (GUM) out-patients clinic
☐ my parents  ☐ the council / social services
☐ other family  ☐ my GP practice (family doctor)
☐ my friends  ☐ an advice or counselling agency
☐ a self-help group  ☐ a telephone helpline
☐ other  ➔ please say who or what

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

☐ No change
☐ Better  ➔ Why?

☐ Worse  ➔ Why?

☐ Been solved or gone away  ➔ Why?

If it has gone or been solved  ➔ GO TO question C9
C6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question C9
☐ yes
☐ don’t know

C7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

C8. Why have you not got this help at the moment? (tick all that apply)

☐ I'm getting all the help that is available
☐ It's not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don't know how to get it
☐ I can’t afford it
☐ I don’t want to use it ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other ➔ please say why not?

___________________________________________________________________________________

C9. 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.
D. HOUSEHOLD CHORES AND LOOKING AFTER YOURSELF

D1. 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 → GO TO question D9
☐ yes

D2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no → 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)

☐ my partner / spouse
☐ an HIV organisation
☐ my children
☐ my HIV (GUM) out-patients clinic
☐ my parents
☐ the council / social services
☐ other family
☐ my GP practice (family doctor)
☐ my friends
☐ an advice or counselling agency
☐ a self-help group
☐ a telephone helpline
☐ other → please say who or what

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

☐ No change

☐ Better → Why?

☐ Worse → Why?

☐ Been solved or gone away → Why?

If it has gone or been solved → GO TO question D9
D6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question D9
☐ yes
☐ don’t know

D7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

D8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________
___________________________________________________________________________________

D9. Currently, how do you feel about your ability to do household chores and/or look after yourself (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.
E. MOBILITY – GETTING ABOUT

E1. In the past 12 months, have you had any problems getting around locally – to hospital, the shops, services, or to see friends etc?

☐ no ➔ GO TO question E9
☐ yes

E2. What problems have you had?
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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)

☐ my partner / spouse
☐ my children
☐ my parents
☐ other family
☐ my friends
☐ a self-help group
☐ other ➔ please say who or what

☐ an HIV organisation
☐ my HIV (GUM) out-patients clinic
☐ the council / social services
☐ my GP practice (family doctor)
☐ an advice or counselling agency
☐ a telephone helpline

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

☐ No change
☐ Better ➔ Why?
☐ Worse ➔ Why?
☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question E9
E6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question E9
☐ yes
☐ don’t know

E7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

E8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It's not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________
___________________________________________________________________________________

E9. Currently, how do you feel about your ability to get around locally (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.
F. MONEY – GETTING ENOUGH TO LIVE ON

F1. In the past 12 months, have you had any problems getting enough money to live on?
   ☐ no ➔ GO TO question F9
   ☐ yes

F2. What problems have you had?
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

F3. In the past 12 months, have you had any help with these problems?
   ☐ no ➔ 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)
   ☐ my partner / spouse
   ☐ my children
   ☐ my parents
   ☐ other family
   ☐ my friends
   ☐ a self-help group
   ☐ other ➔ please say who or what
           □ an HIV organisation
           □ my HIV (GUM) out-patients clinic
           □ the council / social services
           □ my GP practice (family doctor)
           □ an advice or counselling agency
           □ a telephone helpline

F5. Compared to a year ago, have these problems got better, worse or gone away?
   ☐ No change
   ☐ Better ➔ Why?
___________________________________________________________________________________
   ☐ Worse ➔ Why?
___________________________________________________________________________________
   ☐ Been solved or gone away ➔ Why?
___________________________________________________________________________________
   If it has gone or been solved ➔ GO TO question F9
F6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔  GO TO question F9
☐ yes
☐ don’t know

F7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

F8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔  why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔  please say why not?
___________________________________________________________________________________

F9. 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.
G. MANAGING ANXIETY AND DEPRESSION

G1. In the past 12 months, have you had any problems with anxiety or depression?
   □ no ➔ GO TO question G9
   □ yes

G2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

G3. In the past 12 months have you had any help with these problems?
   □ no ➔ 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)
   □ my partner / spouse       □ an HIV organisation
   □ my children               □ my HIV (GUM) out-patients clinic
   □ my parents                □ the council / social services
   □ other family              □ my GP practice (family doctor)
   □ my friends                □ an advice or counselling agency
   □ a self-help group         □ a telephone helpline
   □ other ➔ please say who or what

G5. Compared to a year ago, have these problems got better, worse or gone away?
   □ No change
   □ Better ➔ Why?

   □ Worse ➔ Why?

   □ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question G9

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

☐ no  ➔ GO TO question G9
☐ yes
☐ don’t know

G7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

G8. Why have you not got this help at the moment? (tick all that apply)

☐ I'm getting all the help that is available
☐ It's not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________
___________________________________________________________________________________

G9. 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.
H. PROBLEMS WITH DRUGS OR ALCOHOL

H1. In the past 12 months, have you had any problems related to drugs or alcohol?

☐ no  ➔  GO TO question H9
☐ yes

H2. What problems have you had?
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

H3. In the past 12 months, have you had any help with these problems?

☐ no  ➔  GO TO question H5
☐ yes

H4. Who (or what) has helped you in the last 12 months or is helping you now? (tick all that apply)

☐ my partner / spouse  ☐ an HIV organisation
☐ my children  ☐ my HIV (GUM) out-patients clinic
☐ my parents  ☐ the council / social services
☐ other family  ☐ my GP practice (family doctor)
☐ my friends  ☐ an advice or counselling agency
☐ a self-help group  ☐ a telephone helpline
☐ other  ➔  please say who or what

H5. Compared to a year ago, have these problems got better, worse or gone away?

☐ No change

☐ Better  ➔  Why?

☐ Worse  ➔  Why?

☐ Been solved or gone away  ➔  Why?

If it has gone or been solved  ➔  GO TO question H9
H6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question H9  
☐ yes  
☐ don’t know

H7. Realistically, what help do you think would make a difference? (give one example)
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

H8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available  
☐ It’s not available  
☐ I don’t really need it  
☐ I haven’t asked for it  
☐ I can manage without it  
☐ I don’t know how to get it  
☐ I can’t afford it  
☐ I don’t want to use it  ➔ why not?
___________________________________________________________________________________
___________________________________________________________________________________

☐ other ➔ please say why not?
___________________________________________________________________________________

H9. Currently, how do you feel about your ability to cope with drugs or alcohol related problems (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. RELATIONSHIPS WITH REGULAR PARTNERS

If you have NOT had a regular partner in the last 12 months ➔ GO TO SECTION K (page 24)

J1. In the past 12 months, have you had any problems or difficulties with your relationship with your partner?

☐ no ➔ GO TO question J9
☐ yes

J2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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
☐ an HIV organisation
☐ my children
☐ my HIV (GUM) out-patients clinic
☐ my parents
☐ the council / social services
☐ other family
☐ my GP practice (family doctor)
☐ my friends
☐ an advice or counselling agency
☐ a self-help group
☐ a telephone helpline
☐ other ➔ please say who or what

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

☐ No change
☐ Better ➔ Why?

☐ Worse ➔ Why?

☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question J9
J6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question J9
☐ yes
☐ don’t know

J7. Realistically, what help do you think would make a difference? (give one example)
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

J8. Why have you not got this help at the moment? (tick all that apply)

☐ I'm getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?
___________________________________________________________________________________
___________________________________________________________________________________
☐ other  ➔ please say why not?
___________________________________________________________________________________

J9. 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.
K. LOOKING AFTER CHILDREN

If you do NOT have any children ➔ GO TO SECTION L (page 26)

K1. In the past 12 months, have you had any problems or difficulties looking after your children?

☐ no ➔ GO TO question K9
☐ yes

K2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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)

☐ my partner / spouse
☐ my children
☐ my parents
☐ other family
☐ my friends
☐ a self-help group
☐ other ➔ please say who or what

☐ an HIV organisation
☐ my HIV (GUM) out-patients clinic
☐ the council / social services
☐ my GP practice (family doctor)
☐ an advice or counselling agency
☐ a telephone helpline

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

☐ No change
☐ Better ➔ Why?
☐ Worse ➔ Why?
☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question K9
K6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question K9
☐ yes
☐ don’t know

K7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

K8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________

K9. 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.
**L. FRIENDSHIPS**

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

☐ no ➔ GO TO question L9

☐ yes

**L2. What problems have you had?**

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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)

☐ my partner / spouse

☐ an HIV organisation

☐ my children

☐ my HIV (GUM) out-patients clinic

☐ my parents

☐ the council / social services

☐ other family

☐ my GP practice (family doctor)

☐ my friends

☐ an advice or counselling agency

☐ a self-help group

☐ a telephone helpline

☐ other ➔ please say who or what

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

☐ No change

☐ Better ➔ Why?

☐ Worse ➔ Why?

☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question L9
L6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question L9
☐ yes
☐ don’t know

L7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

L8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________

L9. 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.
M. SEX

M1. In the past 12 months, have you had any problems with your sex life?

☐ no  ➔ GO TO question M9

☐ yes

M2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no  ➔ 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)

☐ my partner / spouse
☐ an HIV organisation
☐ my children
☐ my HIV (GUM) out-patients clinic
☐ my parents
☐ the council / social services
☐ other family
☐ my GP practice (family doctor)
☐ my friends
☐ an advice or counselling agency
☐ a self-help group
☐ a telephone helpline
☐ other  ➔ please say who or what

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

☐ No change

☐ Better  ➔ Why?

☐ Worse  ➔ Why?

☐ Been solved or gone away  ➔ Why?

If it has gone or been solved  ➔ GO TO question M9
M6. With more help or support, do you think you could reduce, or overcome these problems?

- [ ] no  ➔ GO TO question M9
- [ ] yes
- [ ] don’t know

M7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

M8. Why have you not got this help at the moment? (tick all that apply)

- [ ] I’m getting all the help that is available
- [ ] It’s not available
- [ ] I don’t really need it
- [ ] I haven’t asked for it
- [ ] I can manage without it
- [ ] I don’t know how to get it
- [ ] I can’t afford it
- [ ] I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

- [ ] other  ➔ please say why not?

___________________________________________________________________________________
___________________________________________________________________________________

M9. 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.
N. DISCRIMINATION

N1. In the past 12 months, have you experienced any discrimination?

☐ no ➔ GO TO question N9
☐ yes

N2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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)

☐ my partner / spouse
☐ my children
☐ my parents
☐ other family
☐ my friends
☐ a self-help group
☐ other ➔ please say who or what
☐ an HIV organisation
☐ my HIV (GUM) out-patients clinic
☐ the council / social services
☐ my GP practice (family doctor)
☐ an advice or counselling agency
☐ a telephone helpline

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

☐ No change
☐ Better ➔ Why?

☐ Worse ➔ Why?

☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question N9
N6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question N9
☐ yes
☐ don't know

N7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

N8. Why have you not got this help at the moment? (tick all that apply)

☐ I'm getting all the help that is available
☐ It's not available
☐ I don't really need it
☐ I haven't asked for it
☐ I can manage without it
☐ I don't know how to get it
☐ I can't afford it
☐ I don't want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________

N9. Currently, how do you feel about your ability to cope with discrimination?

☐ 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-CONFIDENCE

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

☐ no  ➔ GO TO question P9
☐ yes

P2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no  ➔ 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)

☐ my partner / spouse  ☐ an HIV organisation
☐ my children  ☐ my HIV (GUM) out-patients clinic
☐ my parents  ☐ the council / social services
☐ other family  ☐ my GP practice (family doctor)
☐ my friends  ☐ an advice or counselling agency
☐ a self-help group  ☐ a telephone helpline
☐ other  ➔ please say who or what

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

☐ No change
☐ Better  ➔ Why?

☐ Worse  ➔ Why?

☐ Been solved or gone away  ➔ Why?

If it has gone or been solved  ➔ GO TO question P9
P6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no ➔ GO TO question P9
☐ yes
☐ don’t know

P7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

P8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other ➔ please say why not?

___________________________________________________________________________________

P9. Currently, how do you feel about your self-confidence?

☐ 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. KNOWLEDGE OF HIV TREATMENTS

Q1. In the past 12 months, have you had any problems finding out about HIV treatments?

☐ no ➔ GO TO question Q9
☐ yes

Q2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

Q3. In the past 12 months, have you had any help with these problems?

☐ no ➔ 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)

☐ my partner / spouse
☐ my children
☐ my parents
☐ other family
☐ my friends
☐ a self-help group
☐ other ➔ please say who or what ...
☐ an HIV organisation
☐ my HIV (GUM) out-patients clinic
☐ the council / social services
☐ my GP practice (family doctor)
☐ an advice or counselling agency
☐ a telephone helpline

Q5. Compared to a year ago, have these problems got better, worse or gone away?

☐ No change
☐ Better ➔ Why?

☐ Worse ➔ Why?

☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question Q9
Q6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no ➔ GO TO question Q9
☐ yes
☐ don’t know

Q7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

Q8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other ➔ please say why not?

___________________________________________________________________________________
___________________________________________________________________________________

Q9. Currently, how do you feel about your knowledge of HIV treatments?

☐ 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. ABILITY TO TAKE HIV TREATMENTS REGULARLY

R0. Are you currently taking any anti-HIV treatments?

☐ no and I am not currently thinking of starting ➔ GO TO section S (page 38)
☐ no, but I am thinking of starting ➔ GO TO question R9
☐ yes

R1. In the past 12 months, have you had any problems regularly taking anti-HIV treatments?

☐ no ➔ GO TO question R9
☐ yes

R2. What problems have you had?

___________________________________________________________________________________
___________________________________________________________________________________

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

☐ no ➔ 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)

☐ my partner / spouse
☐ my children
☐ my parents
☐ other family
☐ my friends
☐ a self-help group
☐ other ➔ please say who or what

☐ an HIV organisation
☐ my HIV (GUM) out-patients clinic
☐ the council / social services
☐ my GP practice (family doctor)
☐ an advice or counselling agency
☐ a telephone helpline

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

☐ No change
☐ Better ➔ Why?

☐ Worse ➔ Why?

☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question R9
R6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question R9
☐ yes
☐ don’t know

R7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

R8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________

R9. Currently, how do you feel about your ability to take anti-HIV treatments regularly?

☐ 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. DEALING WITH (HEALTH) PROFESSIONALS  
(such as doctors, nurses, social workers, dentists etc.)

S1. In the past 12 months, have you had any problems dealing with doctors or other health professionals?
☐ no  ➔ GO TO question S9
☐ yes

S2. What problems have you had?
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

S3. In the past 12 months, have you had any help with these problems?
☐ no  ➔ GO TO question S5
☐ yes

S4. 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
☐ a self-help group
☐ other  ➔ please say who or what
☐ an HIV organisation
☐ my HIV (GUM) out-patients clinic
☐ the council / social services
☐ my GP practice (family doctor)
☐ an advice or counselling agency
☐ a telephone helpline

S5. Compared to a year ago, have these problems got better, worse or gone away?
☐ No change
☐ Better  ➔ Why?

☐ Worse  ➔ Why?

☐ Been solved or gone away  ➔ Why?

If it has gone or been solved  ➔ GO TO question S9
S6. With more help or support, do you think you could reduce, or overcome these problems?

☐ no  ➔ GO TO question S9
☐ yes
☐ don’t know

S7. Realistically, what help do you think would make a difference? (give one example)
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

S8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?
___________________________________________________________________________________
___________________________________________________________________________________

S9. Currently, how do you feel about your ability to deal with doctors and other health professionals?

☐ 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.
T. TRAINING AND OPPORTUNITIES

T1. In the past 12 months, have you been interested in learning new skills or retraining?

☐ no ➔ GO TO question T9
☐ yes

T2. What skills have you wanted to learn or improve?
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

T3. In the past 12 months, have you had any training or other help learning new skills?

☐ no ➔ GO TO question T5
☐ yes

T4. Who (or what) has helped you in the last 12 months or is helping you now?
(tick all that apply)

☐ my partner / spouse
☐ an HIV organisation
☐ my children
☐ my HIV (GUM) out-patients clinic
☐ my parents
☐ the council / social services
☐ other family
☐ my GP practice (family doctor)
☐ my friends
☐ an advice or counselling agency
☐ a self-help group
☐ a telephone helpline
☐ other ➔ please say who or what

T5. Compared to a year ago, has your interest in learning new skills / retraining increased, decreased or gone away?

☐ No change
☐ Increased ➔ Why?
☐ Decreased ➔ Why?
☐ Been solved or gone away ➔ Why?

If it has gone or been solved ➔ GO TO question T9
T6. With more help or support, do you think you could further improve your skills?

☐ no  ➔ GO TO question T9
☐ yes
☐ don’t know

T7. Realistically, what help do you think would make a difference? (give one example)

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

T8. Why have you not got this help at the moment? (tick all that apply)

☐ I’m getting all the help that is available
☐ It’s not available
☐ I don’t really need it
☐ I haven’t asked for it
☐ I can manage without it
☐ I don’t know how to get it
☐ I can’t afford it
☐ I don’t want to use it  ➔ why not?

___________________________________________________________________________________
___________________________________________________________________________________

☐ other  ➔ please say why not?

___________________________________________________________________________________

T9. Currently, how do you feel about your opportunities in 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.
U. OTHER NEEDS FOR DAILY LIVING

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

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___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

THANK YOU FOR YOUR TIME!

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