

# 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](http://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](mailto: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](http://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 | <input type="checkbox"/> Indian                |
|                       | <input type="checkbox"/> Pakistani             |
|                       | <input type="checkbox"/> Other, specify: _____ |
| Black / Black British | <input type="checkbox"/> Caribbean             |
|                       | <input type="checkbox"/> African               |
|                       | <input type="checkbox"/> Other, specify: _____ |
| Chinese               | <input type="checkbox"/>                       |
| White                 | <input type="checkbox"/> Irish                 |
|                       | <input type="checkbox"/> British               |
|                       | <input type="checkbox"/> Other, specify: _____ |
| Mixed (ethnic group)  | <input type="checkbox"/> specify: _____        |
| Other                 | <input type="checkbox"/> 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)

- |   |  |
|---|--|
| <input type="checkbox"/> I live alone           | <input type="checkbox"/> I live with friends             |
| <input type="checkbox"/> I live with a partner  | <input type="checkbox"/> I live with other tenants       |
| <input type="checkbox"/> I live with children   | <input type="checkbox"/> I am in temporary accommodation |
| <input type="checkbox"/> I live with my parents | <input type="checkbox"/> 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

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# 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?**

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**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)

- |   |  |
|---|--|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation             |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) clinic             |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services   |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)  |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline            |
| <input type="checkbox"/> other → please say who or what |  |

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

- No change
- Better → Why?

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- Worse → Why?

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- Been solved or gone away → Why?

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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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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?

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Worse → Why?

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Been solved or gone away → Why?

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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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

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

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

- No change
- Better → Why?

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- Worse → Why?

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- Been solved or gone away → Why?

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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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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?**

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Worse → **Why?**

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Been solved or gone away → **Why?**

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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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

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

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

- No change
- Better → Why?

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Worse → Why?

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Been solved or gone away → Why?

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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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

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

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

- No change
- Better → Why?

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- Worse → Why?

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- Been solved or gone away → Why?

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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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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

**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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

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

---

**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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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)**

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**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?**

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- other → **please say why not?**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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)**

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**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?**

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---

- 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?**

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**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)

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

---

**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)**

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**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?**

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- 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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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)**

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**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?**

---

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- 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?**

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**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)

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

**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)**

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**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?

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## 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)

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

## 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)**

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**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?**

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**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)

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

**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)**

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**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?**

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**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)

- |   |   |
|---|---|
| <input type="checkbox"/> my partner / spouse            | <input type="checkbox"/> an HIV organisation              |
| <input type="checkbox"/> my children                    | <input type="checkbox"/> my HIV (GUM) out-patients clinic |
| <input type="checkbox"/> my parents                     | <input type="checkbox"/> the council / social services    |
| <input type="checkbox"/> other family                   | <input type="checkbox"/> my GP practice (family doctor)   |
| <input type="checkbox"/> my friends                     | <input type="checkbox"/> an advice or counselling agency  |
| <input type="checkbox"/> a self-help group              | <input type="checkbox"/> a telephone helpline             |
| <input type="checkbox"/> 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?

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- Decreased → Why?

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- 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)**

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**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.

