

futures five

HIV futures five

A National Survey of People living with HIV/AIDS

This survey is about health, treatments, work, and the financial situation of people living with HIV/AIDS (PLWHA). Policy makers and service providers have told us that they used the findings from the HIV Futures Surveys conducted in 1997, 1999, 2001 and 2003 to ensure that policy and services for HIV positive people were best suited to their needs. This survey will provide up to date information on what living with HIV in Australia is like at the moment, and ensure that education and support services for positive people are the most effective they can be. The HIV Futures Survey is conducted every two years.

The results of this survey will also go direct to the community groups who work with positive people. A community report will also be available to everyone and the results will also appear in publications in the HIV, gay, IDU and mainstream press.

The survey has been developed in consultation with a variety of community groups and it is officially supported by the National Association of People Living with HIV/AIDS (NAPWA) and the Australian Federation of AIDS Organisations (AFAO)

The Researchers on this project are Dr Jeffrey Grierson, Senior Research Fellow and Rachel Thorpe, Research Officer with the Living with HIV Program, Australian Research Centre in Sex, Health and Society, Latrobe University.

The Living with HIV program at the Australian Research Centre in Sex, Health and Society is funded by the Commonwealth Department of Health and Aging to conduct an Australian national program of social research around people living with HIV/AIDS and their carers.

If you would like to have a say about some of the specific issues in the survey at greater length in one of our interview projects or receive a copy of the report that will be prepared on this study, please fill out the attached form and return it in the small (white) reply paid envelope.

Thanks for your time and help.

The team at the Living with HIV Program

www.hivfutures.org.au

Please Note: You may receive multiple copies of this survey, as we are asking a number of organisations to assist with its distribution. Our apologies for any inconvenience this may cause you.



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**This survey is voluntary and completely anonymous –
do not write your name and address on the survey.**

No information will be kept that allows for the identification of any person doing the survey. All the answers you give are confidential. This means that no one apart from the Living with HIV staff will see your answers. The data (without any identifying details) will be kept by Latrobe University for a period of five years for comparison with future studies.

The survey will take between 40 minutes and 1 1/2 hours to complete. You may prefer to take a break between sections of the survey. Remember if there are any questions you do not wish to answer, just skip them.

**When you have completed the survey, please return it to us in the
LARGE reply-paid envelope. You do not need to use any stamps.**

**If you would prefer to complete the survey online,
go to www.hivfutures.org.au**

If you know of anyone else who might be able to complete the survey, please tell them about this study. The more people who answer the survey, the more useful the results will be. Additional copies are available by calling 1800 064 398 or e-mailing hivfutures@latrobe.edu.au or from AIDS Councils, PLWHA organisations and other AIDS organisations.

Some of the questions in the survey are about sensitive and personal matters. If you are uncomfortable about answering any question, just move on to the next one. Skipping a question or section in the survey will not make your other answers less useful. Completing this survey may bring up experiences that have been distressing or questions about the things covered. A list of phone numbers can be found at the end of the survey where you may contact people to discuss these.

If you have any questions about the survey please feel free to contact us: (Jeffrey Grierson or Rachel Thorpe on 1 800 064 398 or by e-mailing hivfutures@latrobe.edu.au)

If you have any complaints or queries that the researcher has not been able to answer to your satisfaction, you may contact:

The Ethics Liaison Officer, Human Ethics Committee, Latrobe University, Bundoora, Victoria, 3083,
(phone: (03) 9479 1443, e-mail: humanethics@latrobe.edu.au).

Please Return the Survey by February 28, 2006

To:
REPLY PAID 73532
HIV Futures
ARCSHS
215 Franklin St.
MELBOURNE VIC 3000
Australia

SECTION A

We would like to know a little about your background. This helps us to find out about differences between groups of positive people

A1 In what year were you born?

A2 Are you of Aboriginal or Torres Strait Islander origin?

No Yes Aboriginal Yes Torres Strait Islander

(For persons of both Aboriginal and Torres Strait Islander origin, mark both 'yes' boxes)

A3 In which country were you born? _____

A3a) What is your official country of residence? _____

A4 Which language do you speak at home? _____

A4a) How would you describe your ancestry?

(e.g. Greek, Italian, Vietnamese- list more than one if necessary)

A5 What is your sex?

Male Female Transgender Other (please specify) _____

A5a) What gender do you identify with?

Male Female None

A6 Which of the following best describes the area in which you live? (tick one box only)

Capital City/Inner suburban Regional centre (population 5,000 or more)
 Outer suburban Rural

A7 What is the postcode or suburb/town where you live? /_____

A7a) How long have you lived in this area? months years

A8 What is the highest level of education you have completed? (tick one box only)

Primary school only Leaving certificate/HSC/Year 12
 Up to 3 years High School Tertiary diploma/Trade certificate/TAFE
 4th form/Year 10 University degree

A9 Do you have any religious or spiritual beliefs? (tick one box only)

No/none/atheist Jewish Anglican/Church of England
 Agnostic Muslim New Age Other Christian
 Catholic Buddhist Other (please specify) _____

A10 How important to you are your religious or spiritual beliefs?

Not important A little important Very important Extremely important

SECTION B

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The following questions are about your living situation. These will tell us about how well suited positive people's accommodation is to their health and lifestyle

B1 Where do you currently live? (tick one box only)

- Own or purchasing house or flat Rent-free (e.g. provided by friends, family, etc.)
 Private rental accommodation Community housing/housing co-operative
 Public rental accommodation (government owned) Other (please describe)
-

B2 Is this accommodation suitable for your current needs?

- Yes (go to B4) No

B3 Why not? (tick as many as apply to you)

- Too expensive Confidentiality problems
 Too small Poor condition of housing
 Lack of privacy Inadequate for my current state of health
 Too far from health services Harassment
 Too far from other services Fear of violence
 Inadequate facilities for carer(s) Other (please describe)
-

B3a) Do you have other accommodation options for the future?

- Yes No

B4 Who do you live with? (tick as many as apply to you)

- No-one Other family members
 Partner/spouse Friend(s)/Flatmate(s)
 Dependent children Other (please specify)
-

B4a) How many people do you live with? Adults Children

B5 Do you have any children?

- Yes No (go to B7)

B6 Please provide some details

	Age	Dependent child?		Living with you?	
Child 1	<input type="checkbox"/>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Child 2	<input type="checkbox"/>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Child 3	<input type="checkbox"/>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Child 4	<input type="checkbox"/>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No

B7 **Have you ever changed your accommodation as a result of having HIV/AIDS?**

- Yes No (*go to B10*)

B8 **Number of times ever** **Number of times in last 2 years**

B9 **The last time you moved why was this?** (*tick as many as apply to you*)

- | | |
|--|--|
| <input type="checkbox"/> Moved to a quieter location | <input type="checkbox"/> Planning for illness |
| <input type="checkbox"/> Needed cheaper housing | <input type="checkbox"/> Better health |
| <input type="checkbox"/> Improved finances | <input type="checkbox"/> Ending of relationship |
| <input type="checkbox"/> Moved closer to friends | <input type="checkbox"/> Beginning of new relationship |
| <input type="checkbox"/> Moved closer to health services | <input type="checkbox"/> Looking for/returned to work |
| <input type="checkbox"/> Moved closer to other services | <input type="checkbox"/> Stopped working |
| <input type="checkbox"/> Moved out of family home | <input type="checkbox"/> To avoid harassment |
| <input type="checkbox"/> Moved in with family | <input type="checkbox"/> Lack of privacy |
| <input type="checkbox"/> Illness | <input type="checkbox"/> Other (<i>please specify</i>) |

B10 **Have you received less favourable treatment than other people in relation to accommodation as a result of having HIV/AIDS?**

- Yes, in the last 2 years (*please specify*) Yes, more than 2 years ago (*please specify*) No

B11 **How many bedrooms does your place of residence have?**

B12 **Do you own, or have access to a car?**

- Yes No

B13 **How easy is it for you to get public transport to and from your home?**

- Very difficult Difficult Easy Very easy

B14 **Do you own any pets?**

- Yes (*please specify number and type, eg. 3 cats and a dog*) No

B15 **What sorts of things do you do to improve your health?** (*tick all that apply*)

- | | | |
|--|--|---|
| <input type="checkbox"/> Exercise | <input type="checkbox"/> Sleep | <input type="checkbox"/> Spending time with partner |
| <input type="checkbox"/> Healthy eating | <input type="checkbox"/> Relaxation | <input type="checkbox"/> Spending time with family |
| <input type="checkbox"/> Taking pills on time | <input type="checkbox"/> Spending time with pets | |
| <input type="checkbox"/> Spending time with friends | <input type="checkbox"/> Complementary therapies | |
| <input type="checkbox"/> Other (<i>please specify</i>) | | |

B16 **What is your height?** cm

B17 **What is your weight?** kgs

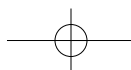
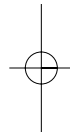
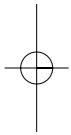


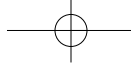
SECTION 6

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This section is about your health, the treatments you take and the way you experience HIV/AIDS. This is a complex area, but we have tried to make the questions as clear as possible. Remember, if you have any questions, please call us on 1800 064 398 (free call).

- C1 In what year did you first test positive for HIV?
- C2 In what year do you think you were infected with HIV?
- C3 Where were you living when you were diagnosed with HIV?
(Postcode or suburb /town) /
- C4 When you first tested positive for HIV why did you take a test at that time? (tick one only)
- | | |
|---|--|
| <input type="checkbox"/> My doctor suggested it | <input type="checkbox"/> Starting a new relationship |
| <input type="checkbox"/> I had a particular risk episode/event | <input type="checkbox"/> Availability of new treatments |
| <input type="checkbox"/> I was a member of a risk group | <input type="checkbox"/> Insurance |
| <input type="checkbox"/> I was tested without my knowledge | <input type="checkbox"/> I became ill |
| <input type="checkbox"/> A contact tracer/other health care worker suggested it | <input type="checkbox"/> As part of a routine health screening |
| <input type="checkbox"/> My partner tested positive | <input type="checkbox"/> I was tested during pregnancy (antenatal) |
| | <input type="checkbox"/> Other (please specify) _____ |
- C5 Did you receive counselling (or a detailed discussion) about HIV before you were tested for HIV?
 Yes No (go to C6)
- C5a) Who provided this counselling? (e.g. GP, Nurse etc.) _____
- C5b) Were you satisfied with the information you received from this person?
 Yes No
- C5c) Were you satisfied with the support you received from this person?
 Yes No
- C6 Did you receive counselling (or a detailed discussion) about HIV after you tested HIV positive?
 Yes No (go to C7)
- C6a) Who provided this counselling? (e.g. GP, Nurse etc.) _____
- C6b) Were you satisfied with the information you received from this person?
 Yes No
- C6c) Were you satisfied with the support you received from this person?
 Yes No
- C7 How do you believe you were infected with HIV? (tick one box only)
- | | |
|---|---|
| <input type="checkbox"/> Sex with a man | <input type="checkbox"/> Blood products |
| <input type="checkbox"/> Sex with a woman | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Injecting drugs | <input type="checkbox"/> Don't know |





C8 How would you describe your current state of physical health? (tick one box only)

Poor Fair Good Excellent

C9 How would you describe your overall sense of well-being? (tick one box only)

Poor Fair Good Excellent

C10 Have you experienced any of the following in the past 12 months?

Lipodystrophy/lipoatrophy	<input type="checkbox"/> Yes <input type="checkbox"/> No	Sleep disorder	<input type="checkbox"/> Yes <input type="checkbox"/> No
Weight loss/underweight	<input type="checkbox"/> Yes <input type="checkbox"/> No	Confusion/memory loss	<input type="checkbox"/> Yes <input type="checkbox"/> No
Low energy/fatigue	<input type="checkbox"/> Yes <input type="checkbox"/> No	Raised cholesterol/triglycerides	<input type="checkbox"/> Yes <input type="checkbox"/> No
Peripheral neuropathy	<input type="checkbox"/> Yes <input type="checkbox"/> No	Diarrhoea	<input type="checkbox"/> Yes <input type="checkbox"/> No
Nausea/vomiting	<input type="checkbox"/> Yes <input type="checkbox"/> No	Insulin resistance	<input type="checkbox"/> Yes <input type="checkbox"/> No

C11 Have you ever been diagnosed with an AIDS-defining illness? (eg PCP, Kaposi's Sarcoma)

No (go to C12) Yes (please specify and where possible include year of diagnosis)

_____ year

_____ year

_____ year

_____ year

C12 Have you ever experienced any other HIV-related illnesses ?

No (go to C13) Yes (please specify and where possible include year of diagnosis)

_____ year

_____ year

_____ year

_____ year

C13 Do you have any major health conditions other than HIV/AIDS?

No (go to C14) Yes (please specify and where possible include year of diagnosis)

_____ year

_____ year

_____ year

_____ year

C14 Have you been diagnosed with any mental health conditions?

No (go to C15) Yes

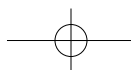
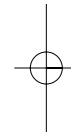
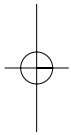
Depression year

Anxiety year

Other condition (please specify and where possible include year of diagnosis)

_____ year

_____ year



T-CELL (CD4) AND VIRAL LOAD TESTING

C15 Have you ever had a T-cell (CD4) test?

- Yes No - why not? _____ (go to C21)
 Don't know (go to C21)

C16 What was the result of your most recent test? cells/ μ L

C17 When was this test? month year

C18 What was your lowest ever T-cell (CD4) count? cells/ μ L

C19 When was this test? month year

C20 In the past 12 months, has your T-cell (CD4) count:

- stayed the same gone up and down don't know
 increased decreased

C21 Have you ever had a viral load test?

- Yes No - why not? _____ (go to C28)
 Don't know (go to C28)

C22 What was the result of your most recent viral load test?

- Undetectable or copies/mL

C23 When was this test? month year

C24 What was your highest ever viral load? Undetectable or copies/mL

C25 When was this test? month year

C26 How many viral load tests have you had in the last 12 months?

C27 In the past 12 months, has your viral load:

- stayed the same gone up and down don't know
 increased decreased

C28 Have you had a viral resistance test? Yes No (go to C29)

C28a) When was your last resistance test? month year

C28b) At the time of this test, what was your:

Viral load? Undetectable or copies/mL T-cell count cells/ μ L

C28c) Did this test find resistance to any antiretroviral drug? Yes No

C28d) Did you change treatments as a result of this test? Yes No

C28e) Did your viral load change following this?

- No Yes, Decreased Yes, Increased I don't know

C28f) Did your CD4 count change following this?

- No Yes, Decreased Yes, Increased I don't know

- C29 Have you ever had hepatitis A? Yes No
- C30 Have you ever been vaccinated against hepatitis A? Yes No
- C31 Have you ever been vaccinated against hepatitis B? Yes No
- C32 Have you ever had hepatitis B? Yes No (go to C33)

HB1) Do you currently experience any hepatitis B related symptoms?

- Yes No Don't know/Not sure

Please specify symptoms:

HB2) What is your current hepatitis B status?

- The virus has been cleared
- I have ongoing hepatitis B infection (carrier status/ surface antigen)
- I have chronic hepatitis B
- Other (please specify)
-

The following questions are about hepatitis C diagnosis. There are two different ways people with HIV can have hep C diagnosed.

C33 Have you ever been tested for hepatitis C

- No test ever
- Yes, had a hep C antibody test
 year of first test year of most recent test
- Yes, had a diagnostic PCR
 year of first test year of most recent test
- Yes, don't know what test
 year of first test year of most recent test

C33a) Have you ever had hepatitis C?

- Yes No

The following questions are for people who have had, or still have the hepatitis C virus. *If you have never had the hepatitis C virus please go to HV1 on page 11.*

HC1) What year were you first diagnosed with hepatitis C?

HC2) What year do you believe you were infected with hepatitis C?

HC3) How do you believe you were infected with hepatitis C? (tick one box only)

- Blood transfusion/ Blood Products During Sex Don't know
- Injection Drug Use (IDU) Tattooing Other (please specify)
- Body Piercing
-

HC4) Have you had a hep C Genotype test?

- Yes No (go to HC5)

HC4a) What was the result of this test?

- Type 1 Type 2 Type 3 Type 4, 5 or 6 Don't know

HC5) Have you taken any of the following treatments for hepatitis C

- Interferon (monotherapy) No
 Currently taking it
 Completed treatment: Year
 Taken previously but not completed: Year

- Interferon/ Pegylated Interferon and Ribavirin No
 Currently taking it
 Completed treatment: Year
 Taken previously but not completed: Year

- Complementary medicines No
 Currently (please specify) _____
 Previously (please specify) _____

Other treatments (please specify) _____

HC6) Do you currently see a doctor for Hep C treatment/management? (tick one only)

- I do not see a doctor for hep C I see a separate Hep C Doctor/specialist
 I see my primary HIV doctor

HC7) Do HIV community services meet your needs as someone with HIV and hep C?

- Yes No
 If No why not?
 They have a poor understanding of hep C co-infection
 They have a poor understanding of IDU issues
 I don't want to disclose my Hep C status
 I don't want to disclose that I have injected drugs
 Other (please specify) _____

HC8) Do you currently experience any hepatitis C related symptoms?

- Yes No Don't know/ Not sure

Please specify symptoms: _____

HC9) Since being diagnosed with hep C, have you ever tested negative on a PCR test?

- Yes, year No Don't know/ Not sure

The following questions are for people who have had hepatitis A, B or C

HV1) Have you had a Liver Function Test (LFT)?

Yes No (go to HV2)

HV1a) When was your most recent LFT? month year

HV1b) What was the result?

Normal ALT

Abnormal ALT

Don't know

HV2) Have you had a Liver Biopsy Test?

Yes No (go to C34)

HV2a) When was your most recent test? month year

HV2b) What was the result?

Liver Fibrosis: Stage?

No Liver Fibrosis

Don't know

The following questions are for everyone.

C34) Have you had a bone density test

Yes, in the last 2 years Yes, more than 2 years ago No

C35) Have you had a fasting cholesterol test?

Yes, in the last 2 years Yes, more than 2 years ago No

C36) Apart from Antiretroviral therapy, are you currently using any other prescribed medication

(e.g. contraceptives, Insulin, HRT, antidepressants)

Yes (Please specify) _____ No

C37) How many times per day do you take:

antiretroviral drugs

complementary therapies

medication for health conditions not related to HIV/AIDS

C38) How many times in total do you have to take medication of any kind per day?

C39) In the last 6 months have you used any treatments (prophylaxis) to prevent opportunistic infections (e.g. PCP)?

Yes No Don't know

C40) In the last 6 months have you taken any medications for anxiety?

(e.g. Valium, Ducene, Antenex, Ativan, Xanax, Kalma, Murelax, Serepax)

Yes No

C41 In the last 6 months have you taken any medications for depression?
 (e.g. Tofranil, Tryptanol, Prothiaden, Sinequan, Deptran, Anafranil, Tolvon, Serzone, Zactin, Lovan, Prozac, Zoloft, Aropax, Cipramil, Efexor, Aurorix, Luvox)

Yes No

C42 In the last 6 months have you taken any of the following medications for your nerves?
 (e.g. Largactil, Melleril, Stelazine, Serenace, Risperdal, Zyprexa, Haldol, Modecate)

Yes No

C43 Have you used any of the following therapies over the past 6 months?

Yes (tick as many as apply) No (go to C45)

- Vitamin/mineral supplements (please specify) _____
- Herbal therapies/supplements (please specify) _____
- Traditional Chinese Medicine (please specify) _____
- Other traditional Medicine (please specify) _____
- Massage
- Meditation/visualisation
- Acupuncture
- Marijuana for therapeutic purposes
- Other complementary or alternative therapies (please specify) _____

C44 Where do you get these therapies (tick as many as apply to you)

- AIDS community organisation PLWHA organisation
- Private practice Health Service
- Health food shop Other (please specify) _____

C45 Please indicate whether you agree or disagree with the following statements

	strongly disagree	disagree	agree	strongly agree	don't know
Complementary therapies can delay the onset of illness due to HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapies can improve well-being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapies can reduce the side effects of conventional medical treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is not enough evidence to be sure about the benefits of complementary therapies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicine's focus on anti-HIV drugs is very limited.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapies can boost the immune system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapies are a central part of my anti-HIV treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next three questions are for women only, men please go to C49.

C46 Have you ever had a cervical (pap) smear test?

Yes (go to C49) No - why not? _____

C47 How many pap smear tests have you had in the last 12 months?

C48 What was the result of your most recent pap smear test?

Everyone should answer the following questions.

By 'antiretroviral drugs' we mean a class of therapies including drugs such as:

- Nucleoside analogues: AZT (zidovudine, Retrovir), 3TC (Lamivudine, Epivir), ddI (Videx), ddC (Hivid), d4T (stavudine, Zerit), 1592 (abacavir, Ziagen), Combivir (AZT & 3TC - which is counted as two antiretrovirals), Trizavir (AZT & 3TC & abacavir - counted as three antiretrovirals).
- Protease inhibitors: saquinavir (Invirase, Fortavase), indinavir (Crixivan), ritonavir (Norvir), nelfinavir (Viracept), Kaletra (lopinavir & ritonavir), amprenavir (Agenerase).
- Non-nucleoside reverse transcriptase inhibitors: nevirapine (Viramune), delavirdine (Rescriptor), efavirenz (Sustiva, Stocrin).
- Nucleotide reverse transcriptase inhibitors: tenofovir (Viread)
- Other antiretroviral drugs: T-20 (enfuvirtide, Fuzeon), atazanavir (Reyataz), Tipranavir

When we talk about 'combination therapy', we mean any two or more antiretroviral drugs taken together

C49 Please indicate how you feel about the following statements:

	strongly disagree	disagree	agree	strongly agree	don't know
I am healthy now and don't need to use combination antiretroviral drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Combination antiretroviral drugs are harmful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Combination antiretroviral drugs are ineffective	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is easy for me to get combination antiretroviral drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New treatments will be developed in time for me to gain benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV treatments will stop me dying from AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor knows a lot more about the treatment of HIV than I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People with HIV should start using antiretroviral drugs as soon as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information on the internet about living with HIV is unreliable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information on the internet about treatment side effects is unreliable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor and I work together to find the best treatment for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The side-effects of antiretroviral drugs outweigh the benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical treatments for HIV/AIDS make safe sex less important than it was	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be willing to participate in HIV vaccine trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C50 Do you believe that combination antiretroviral drugs mean better prospects for most people with HIV?

- Yes
 No
 It's too soon to tell
 Don't know

C51 Do you think that people in your circle of friends believe that these drugs mean better prospects for most people with HIV?

- Yes No They believe it's too soon to tell Don't know

HIV positive people have different experiences with antiretroviral drugs, some have never taken them, others have started and then stopped, and others have changed drugs many times. There are different sections for people who have different experiences of using antiretroviral drugs

C52 What is your experience of HIV treatments?

- Currently taking antiretroviral drugs for HIV
 Have taken antiretroviral drugs for HIV in the past, but not currently taking them
 Never taken antiretroviral drugs for HIV (go to C97 on page 20)

C53 When did you start using antiretroviral drugs? month year

If you are not currently using antiretroviral drugs but have used them in the past, please go to C84 on page 18. If you are currently using antiretroviral drugs, please continue.

C54 How long have you been using antiretroviral drugs? months years

C55 Which of the following drugs are you currently using? (tick as many as apply)

- | | |
|--|--|
| <input type="checkbox"/> AZT (zidovudine, Retrovir) | <input type="checkbox"/> ritonavir (Norvir) |
| <input type="checkbox"/> 3TC (lamivudine, Epivir) | <input type="checkbox"/> nelfinavir (Viracept) |
| <input type="checkbox"/> Combivir (AZT & 3TC) | <input type="checkbox"/> nevirapine (Viramune) |
| <input type="checkbox"/> Trizivir (AZT & 3TC & abacavir sulfate) | <input type="checkbox"/> delavirdine (Rescriptor) |
| <input type="checkbox"/> ddI (Didanosine, Videx) | <input type="checkbox"/> efavirenz (Sustiva, Stocrin) |
| <input type="checkbox"/> ddI ec (Videx ec, didanosine ec) | <input type="checkbox"/> tenofovir (Viread) |
| <input type="checkbox"/> ddC (zalcitabine, Hivid) | <input type="checkbox"/> T-20 (enfuvirtide, Fuzeon) |
| <input type="checkbox"/> d4T (stavudine, Zerit) | <input type="checkbox"/> Kaletra (lopinavir and ritonavir) |
| <input type="checkbox"/> 1592 (abacavir sulfate, Ziagen) | <input type="checkbox"/> atazanavir (Reyataz) |
| <input type="checkbox"/> saquinavir (Invirase, Fortovase) | <input type="checkbox"/> Tipranavir |
| <input type="checkbox"/> indinavir (Crixivan) | <input type="checkbox"/> Interleukin-2 (IL-2, Proleukin) |
| <input type="checkbox"/> amprenavir (Agenerase) | <input type="checkbox"/> Other (please specify) |

C56 For what period does your antiretroviral prescription usually last?

weeks months

C57 Who prescribes your antiretroviral drugs? (tick as many as apply)

- HIV GP/S100 Prescriber Doctor at sexual health centre
 Other GP Other doctor
 HIV specialist at outpatient clinic Other (please specify)
 HIV specialist while an inpatient at hospital

C58 How many different places do you have to go to in order to collect all your prescriptions/drugs?

(please include all medications including complementary therapies and drugs for other health conditions)

C59 How difficult is it for you to do this?

- Not at all difficult Somewhat difficult Very difficult

C60 Do you experience any other difficulties in taking antiretroviral drugs?

- No *(go to C61)* Yes *(tick as many as apply)*
- Remembering to take drugs on time
 - Organising meals around medication
 - Taking a large number of tablets
 - Taking medication in public
 - Carrying/transporting medication
 - Antiretroviral drugs make it difficult to take medication for other health conditions
 - Medication taken for other health conditions makes it difficult to take antiretroviral drugs
 - Side effects *(please specify)* _____
 - Other *(please specify)* _____

C61 Since you started taking antiretroviral drugs has your physical health:

- stayed the same improved fluctuated deteriorated

C62 Since you started taking antiretroviral drugs has your overall feeling of well-being:

- stayed the same improved fluctuated deteriorated

C63 Please indicate how you feel about the following statements:

	strongly disagree	disagree	agree	strongly agree	don't know
I am worried that in the future my medication will stop working for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking tablets gives me an unwanted reminder that I have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C64 How many doses (dose times) of antiretroviral drugs did you miss yesterday?

- None One Two Three Four Five or more

C65 How many doses (dose times) of antiretroviral drugs did you miss the day before yesterday?

- None One Two Three Four Five or more

C66 Have you ever taken a break from your antiretroviral treatments (had a drug holiday)?

- Yes No *(go to C76)*

Thinking about the LAST TIME you took a break from your antiretroviral treatments:

C67 **When did you start the treatment break?** month year

C68 **How long was the break?** days months I am still on the break

C68a) Just before taking this break, what was your:

T-cell (CD4) count? cells/ μ L

Viral load? Undetectable or copies/mL

C69 **Did you have lifestyle (non-medical) reasons for taking a treatment break the last time you did so?**

Yes No (go to C70)

C69a) What were these reasons? (tick as many as apply)

- | | |
|---|---|
| <input type="checkbox"/> It didn't fit my lifestyle | <input type="checkbox"/> The financial burden became too heavy |
| <input type="checkbox"/> A special event | <input type="checkbox"/> Taking drugs at the right time was too difficult |
| <input type="checkbox"/> Clean out my system | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Travel | |

C70 **Did you have clinical reasons for taking a treatment break the last time you did so?**

Yes No (go to C71)

C70a) What were these reasons? (tick as many as apply)

- | | |
|--|---|
| <input type="checkbox"/> Drug resistance developed | <input type="checkbox"/> Recommended by my doctor |
| <input type="checkbox"/> Side effects became too severe | <input type="checkbox"/> Recommended by other health professional |
| <input type="checkbox"/> Changing regimens | <input type="checkbox"/> Liver toxicity problems |
| <input type="checkbox"/> Complications with Hep C | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Taking part in a clinical trial | |

C71 **What type of break was this? (tick one box only)**

Structured Treatment Interruption Treatment Break Other _____

C72 **Did you talk to your HIV doctor about this before taking this break?** Yes No

C73 **Did you talk to your HIV doctor about this while taking this break?** Yes No

C74 **Did you talk to your HIV doctor about this after taking this break?** Yes No

C75 **As a result of your treatment break:**

Did your general health:

stay the same improve fluctuate get worse

Did your sense of well-being:

stay the same improve fluctuate get worse

Did your viral load:

stay the same increase go up and down decrease

Did your CD4 count:

stay the same increase go up and down decrease

Answer the following questions if you are currently taking more than one antiretroviral drug. *If you are currently taking only one antiretroviral drug, please go to section D on page 21.*

C76 When did you start using combination therapy? month year

C77 What was your viral load just before you started combination therapy?

Undetectable or copies/mL

C78 What was your T- cell (CD4) count just before you started combination therapy?

cells/ μ L

C79 Did any of the following occur just before you started combination therapy?

(tick as many as apply to you)

- I had a big rise in my viral load
- I had a big drop in my T-cell (CD4)count
- I became very ill.
- Information showed that this treatment is effective
- I was hospitalised due to HIV-related infections
- A number of my positive friends started this treatment
- My doctor advised me to begin this treatment
- A treatments officer advised me to begin this treatment
- My partner advised me to begin this treatment
- Close friends advised me to begin this treatment
- New drugs became available
- I had just tested positive to HIV
- Other *(please specify)*

C80 Since beginning combination antiretroviral therapy, approximately how many different combinations of drugs have you used?

C81 In the past 12 months, how many different combinations of antiretroviral drugs have you used?

C82 What best describes the last time you changed from one combination to another combination? *(tick one only)*

- I have not changed combinations
- They were not working for me
- Side effects became too severe
- Taking drugs at the right time was too difficult
- The financial burden became too heavy
- Drug resistance developed
- It didn't fit my lifestyle
- Other *(please specify)*

C83 With the antiretroviral drugs currently available, how many other combinations of antiretroviral drugs are available to you for your future treatment?

- None One A few Many Don't know

Only answer the following questions if you are not currently taking antiretroviral drugs but have taken them in the past

- C84 How long did you use these drugs for? months years
- C85 When did you stop using these drugs? month year
- C86 When you decided to stop using antiretroviral drugs, how many antiretroviral drugs were you using?
- C87 Did you experience difficulties with any of the following while taking antiretroviral drugs?
(tick as many as apply to you)
- No (go to C88) Yes (tick as many as apply)
- Remembering to take drugs on time
- Organising meals around medication
- Taking a large number of tablets
- Taking medication in public
- Carrying/transporting medication
- Antiretroviral drugs make it difficult to take medication for other health conditions
- Medication taken for other health conditions makes it difficult to take antiretroviral drugs
- Side effects (please specify) _____
- _____
- Other (please specify) _____
- _____
- C88 While you were taking antiretroviral drugs did your physical health:
- stay the same improve fluctuate deteriorate
- C89 While you were taking antiretroviral drugs did your overall feeling of well-being:
- stay the same improve fluctuate deteriorate
- C90 Approximately how many different combinations of antiretroviral drugs have you ever used?
- C91 What best describes the last time you changed from one combination to another combination? (tick one only)
- I have not changed combinations The financial burden became too heavy
- They were not working for me Drug resistance developed
- Side effects became too severe It didn't fit my lifestyle
- Taking drugs at the right time was too difficult Other (please specify) _____

C92 Did you have lifestyle (non-medical) reasons for stopping treatment?

- Yes No (go to C93)

C92a) What were these reasons? (tick as many as apply)

- | | |
|---|---|
| <input type="checkbox"/> It didn't fit my lifestyle | <input type="checkbox"/> The financial burden became too heavy |
| <input type="checkbox"/> A special event | <input type="checkbox"/> Taking drugs at the right time was too difficult |
| <input type="checkbox"/> Clean out my system | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Travel | |

C93 Did you have clinical reasons for stopping treatment?

- Yes No (go to C94)

C93a) What were these reasons? (tick as many as apply)

- | | |
|--|---|
| <input type="checkbox"/> Drug resistance developed | <input type="checkbox"/> Recommended by my doctor |
| <input type="checkbox"/> Side effects became too severe | <input type="checkbox"/> Recommended by other health professional |
| <input type="checkbox"/> Changing regimens | <input type="checkbox"/> Liver toxicity problems |
| <input type="checkbox"/> Complications with Hep C | <input type="checkbox"/> This is a treatment break |
| <input type="checkbox"/> Taking part in a clinical trial | <input type="checkbox"/> Other (please specify) _____ |

C94 Did you talk to your HIV doctor about this before stopping treatment?

- Yes No

C95 Have you talked to your HIV doctor about this since stopping treatment?

- Yes No

C96 As a result of stopping treatment:

Has your general health:

- stayed the same improved fluctuated become worse

Has your sense of well-being:

- stayed the same improved fluctuated become worse

Has your viral load:

- stayed the same increased gone up and down decreased

Has your CD4 count:

- stayed the same increased gone up and down decreased

Only answer the following questions if you are not currently taking antiretroviral drugs

C97 **Would you consider using antiretroviral drugs at any time in the future?**

- Yes No - why not? _____

C98 **Why would you consider using them? (tick as many as apply to you)**

- If I had a significant rise in my viral load
 If I had a significant drop in T-cell (CD4) count
 If I became very ill
 If information showed that combination therapy is effective
 If I was hospitalised due to HIV-related infections
 If a number of my positive friends began to take up combination therapy
 If my doctor advised me to begin this treatment
 If a treatments officer advised me to begin this treatment
 If my partner advised me to begin this treatment
 If close friends advised me to begin this treatment
 If new drugs became available
 When my break from treatment is finished
 Other (*please specify*) _____

SECTION D *future five*
 This section deals with the ways in which positive people interact with services and communities.

D1 Please indicate which of the following are important sources of information for you about **HIV/AIDS treatments and/or health management** (eg treatments, side effects, illness, other medical info/services etc), and about **living with** HIV/AIDS day to day (eg emotional support, welfare information, housing, other non-medical services).

	Important source of information about:	Important source of information about:
	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
AIDS Council staff (treatments-specific)	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
AIDS Council staff (others)	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
PLWHA Organisation staff (treatments-specific)	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
PLWHA Organisation staff (others)	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Peer support officer	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Positive Women's Organisation	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Positive Heterosexuals Organisation	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Other HIV/AIDS Organisation staff	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
HIV GP/S100 Prescriber	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Other GP	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
HIV specialist	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Sexual Health Service	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Nurse	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Pharmacist	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Dentist	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Dietician	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Liver Specialist	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Complementary therapist	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Sex worker Organisation	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Publications from HIV/AIDS groups	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
HIV magazine/newspaper	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Articles in gay press	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Publications from other sources	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Internet	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
HIV positive friends	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Other friends	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Partner/lover	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Family	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV
Other (please specify)	<input type="checkbox"/> Treatments/Management	<input type="checkbox"/> Living with HIV

D2 From the list above, select your three most important sources of information about **HIV/AIDS treatments and/or health management**.

1 _____ 2 _____ 3 _____

D3 From the list above, select your three most important sources of information about **living with HIV/AIDS**.

1 _____ 2 _____ 3 _____

D4 Does lack of information make it difficult for you to make decisions about any of the following?

- No (*go to D5*) Yes (*tick as many as apply*)
- | | |
|--|--|
| <input type="checkbox"/> Using antiretroviral drugs | <input type="checkbox"/> Financial planning |
| <input type="checkbox"/> Changing antiretroviral drugs | <input type="checkbox"/> Legal issues |
| <input type="checkbox"/> Managing side effects of antiretrovirals | <input type="checkbox"/> Having children |
| <input type="checkbox"/> Taking a break from antiretroviral drugs | <input type="checkbox"/> Work/employment |
| <input type="checkbox"/> Interactions between antiretroviral drugs and other medications | <input type="checkbox"/> Using complementary therapies |
| <input type="checkbox"/> Recreational (party) drug use | <input type="checkbox"/> Other (<i>please specify</i>) _____ |

D5 Who do you usually see for your main general medical treatment? (*tick one box only*).

- | | |
|--|--|
| <input type="checkbox"/> HIV GP/S100 Prescriber | <input type="checkbox"/> Doctor at sexual health centre |
| <input type="checkbox"/> Other GP | <input type="checkbox"/> Other doctor |
| <input type="checkbox"/> HIV specialist at outpatient clinic | <input type="checkbox"/> Other (<i>please specify</i>) _____ |
| <input type="checkbox"/> HIV specialist while an inpatient | |

D6 Does this doctor know your HIV status?

- Yes No

D7 Who do you usually see for your main HIV-related treatment? (*tick one box only*).

- The same doctor as I see for general medical treatment (*as in D5 above*)
- A different doctor (*please tick one of the boxes below*)
- | | |
|--|--|
| <input type="checkbox"/> HIV GP/S100 Prescriber | <input type="checkbox"/> Doctor at sexual health centre |
| <input type="checkbox"/> Other GP | <input type="checkbox"/> Other doctor |
| <input type="checkbox"/> HIV specialist at outpatient clinic | <input type="checkbox"/> Other (<i>please specify</i>) _____ |
| <input type="checkbox"/> HIV specialist while an inpatient | |

D8 Where do you see this doctor/service? (Postcode or suburb/town)

/ _____

D8a Do you have a Medicare card?

- Yes No, I am ineligible No, other _____

D9 In the past six months which of the following services have you used? (*tick as many as apply*).

- | | |
|--|--|
| <input type="checkbox"/> HIV GP/S100 Prescriber | <input type="checkbox"/> Other doctor |
| <input type="checkbox"/> Other GP | <input type="checkbox"/> AIDS organisation social worker |
| <input type="checkbox"/> HIV specialist at outpatient clinic | <input type="checkbox"/> AIDS organisation support worker |
| <input type="checkbox"/> HIV specialist while an inpatient | <input type="checkbox"/> Dentist |
| <input type="checkbox"/> HIV/AIDS organisation clinic | <input type="checkbox"/> Employment agency |
| <input type="checkbox"/> Hospital social worker/Counsellor | <input type="checkbox"/> HIV peer support group |
| <input type="checkbox"/> HIV peer support officer | <input type="checkbox"/> Liver Specialist (Hepatologist) |
| <input type="checkbox"/> Hep C Organisation | <input type="checkbox"/> PLWHA Organisation |
| <input type="checkbox"/> Doctor at sexual health centre | <input type="checkbox"/> IDU organisation |
| | <input type="checkbox"/> Other (<i>please specify</i>) _____ |

D10 Have you ever experienced less favourable treatment than other people at medical services as a result of having HIV/AIDS?

- No (go to D11) Yes, in the last 2 years Yes, more than 2 years ago

D10a) What form did this less favourable treatment take (tick all that apply)

- Harassment Refusal of treatment
 Avoidance Additional Infection Control measures
 Being rushed through Confidentiality problems
 Being treated last Other (please specify) _____
 Abuse

D11 Have you ever experienced less favourable treatment than other people at medical services as a result of having hepatitis C?

- Not Applicable (I do not have hep C) (go to D12) Yes, in the last 2 years
 No (go to D12) Yes, more than 2 years ago

D11a) What form did this less favourable treatment take (tick all that apply)

- Harassment Refusal of treatment
 Avoidance Additional Infection Control measures
 Being rushed through Confidentiality problems
 Being treated last Other (please specify) _____
 Abuse

D12 Which publications containing HIV information do you read? (tick as many as apply to you)

- HIV Australia Spin
 Positive Living (National) National Haemophilia
 Positive Life (PL) (WA) QPP Alive
 User's News Overseas magazines (e.g. Poz)
 Newsletters from community organisations Gay newspapers
 Talkabout Gay magazines
 Other (please specify) _____

CL1) Have you been involved in a clinical trial for HIV related treatment in the last 2 years?

- Yes No (if no go to D13)

CL2) What treatment was this

CL3) How long were you on the trial? months I am still on the trial

CL4) Which of the following describe your decision to enter the trial? (tick all that apply)

- I had no other treatment options
 My other treatments were not working
 My doctor and I decided together
 I felt pressured to go on the trial
 I felt I had enough information about the trial
 It was the only way I could get the treatment
 I felt my experience could benefit others
 Other (please specify) _____

D13 Who have you told about your HIV status? (tick as many as apply to you)

- | | |
|---|--|
| <input type="checkbox"/> No-one | <input type="checkbox"/> Parents |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Brothers and/or sisters |
| <input type="checkbox"/> Positive friends | <input type="checkbox"/> Neighbours |
| <input type="checkbox"/> Close friends | <input type="checkbox"/> People from my ethnic community/group |
| <input type="checkbox"/> Other friends | <input type="checkbox"/> Work colleagues |
| <input type="checkbox"/> Son/s – daughter/s - how old were they when you told them? | |
| <input type="checkbox"/> <input type="checkbox"/> years | <input type="checkbox"/> <input type="checkbox"/> years |
| <input type="checkbox"/> <input type="checkbox"/> years | <input type="checkbox"/> <input type="checkbox"/> years |

D14 Has your HIV status been disclosed to other people when you did not want it to be?

- Yes, in the last 2 years No (if no go to D15)
- Yes, more than 2 years ago

D14a) Who disclosed your status?(tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> HIV positive friends |
| <input type="checkbox"/> Parents | <input type="checkbox"/> Close friends |
| <input type="checkbox"/> Brothers and/or sisters | <input type="checkbox"/> Other friends |
| <input type="checkbox"/> Son/daughter | <input type="checkbox"/> People from my ethnic community |
| <input type="checkbox"/> Other family | <input type="checkbox"/> Neighbours |
| <input type="checkbox"/> Work colleagues | <input type="checkbox"/> Worker in a health care setting |
| <input type="checkbox"/> Community organisation staff/volunteers | |
| <input type="checkbox"/> Other (please specify) | |

D14b) Did this disclosure have a negative effect on you?

- Yes No

D15 Do you personally know any other people who are HIV positive? (tick as many as apply to you)

- | | |
|--|---|
| <input type="checkbox"/> No-one | <input type="checkbox"/> Son/daughter |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Other relative |
| <input type="checkbox"/> Former partner/Spouse | <input type="checkbox"/> Acquaintance/member of support group |
| <input type="checkbox"/> Friend | <input type="checkbox"/> Other (please specify) |

D16 Have you been involved with the care or nursing of a person with HIV/AIDS in the last 2 years?

- Yes No

D17 Has anyone close to you ever died of AIDS? (tick as many as apply)

- | | |
|--|--|
| <input type="checkbox"/> No-one | <input type="checkbox"/> Son/daughter |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Other relative |
| <input type="checkbox"/> Former partner/Spouse | <input type="checkbox"/> Acquaintance |
| <input type="checkbox"/> Friend | <input type="checkbox"/> Member of support group |

D18 How much of your free time is spent with other HIV positive people?

- None A little Some A lot

D19 Are you considering having a child? (tick one only)

- No
- No, I already have children
- I have decided to have a child/children in the future
- I am currently trying to conceive/get pregnant
- I am currently pregnant
- I have thought about it but I haven't decided
- I have thought about it but I have decided that it is too risky
- I was told not to by a doctor/ medical professional
- I don't have enough information to make a decision
- Other *(please specify)*

D20 In making major decisions about your life, how far ahead do you make plans? (tick one only)

- One day at a time
- A few months ahead
- 1 year ahead
- 5 years into the future
- 10 or more years into the future

D21 Has this changed in the last two years?

- Yes
- No *(go to D24)*

D22 How far ahead did you make plans two years ago? (tick one box only)

- One day at a time
- A few months ahead
- 1 year ahead
- 5 years into the future
- 10 or more years into the future

D23 What was the main cause of this change? (tick one box only)

- Taking up new treatments
- Improved health due to taking up new treatments
- Improved health due to other reasons
- The possibility of taking up new treatments
- Declining health
- Other *(please specify)*

D24 When you think about all the things that make you who you are, how important are each of the following aspects of yourself?

	essential	important	not important	irrelevant
HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexuality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gender	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug use (recreational/illegal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ethnicity/Cultural background	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parenthood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Career	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Religious beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>(please specify)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D25 Generally, how much support do you have from the sources listed below?

	a lot	some	a little	none	does not apply
Your partner/spouse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your HIV positive friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your close friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your other friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your brothers and/or sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your pets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PLWHA groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health care workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Volunteer carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Religious or spiritual adviser	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D26 Please indicate how you feel about the following statements:

	strongly agree	agree	disagree	strongly disagree
Looking after my physical fitness is an important part of managing my HIV infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I cry or feel like crying all the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't enjoy things the way I used to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeping an optimistic frame of mind is an important part of managing HIV infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have lost interest in other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
As long as I am well I prefer not to think about HIV/AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in my body due to HIV/AIDS have made me feel sexually unattractive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ejaculating (cumming) in someone's mouth is risky for HIV transmission	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't feel it's worth going on.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the way my body looks.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Life has become more meaningful since I became HIV positive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healthy eating is an important part of managing my HIV infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Body changes due to lipodystrophy make it obvious to others that people have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D27 Do you have contact with any HIV/AIDS-related organisations? Yes (Go to D29) No

D28 Do any of the following apply to you? (tick as many as apply to you)

<input type="checkbox"/> I do not know how to join	<input type="checkbox"/> No transport/too far away
<input type="checkbox"/> I feel excluded from them	<input type="checkbox"/> I do not have enough time
<input type="checkbox"/> I do not want to be involved	<input type="checkbox"/> Other (please specify) _____

(Go to D31)

D29 What is your involvement in these organisations (tick as many as apply)

- I am an employee I receive newsletters and mail-outs
 I am a member I am a volunteer hours per week
 I am a client/use their services

D30 Which HIV/AIDS organisation(s) do you have contact with?

D31 Have you ever held a decision-making position in an HIV/AIDS-related organisation?

- No Yes, in the last 12 months Yes, more than 12 months ago

D32 Please indicate which of the following services you use through HIV/AIDS-related organisations and which services you use through other organisations (e.g. community services)

	Use this service through an HIV/AIDS organisation	Use this service through another organisation
Treatments advice	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Counselling	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Financial advice	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Financial assistance	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Peer support group	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Informal peer support	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Social contact with other PLWHA	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Pharmacy services	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Complementary therapies (e.g. massage)	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Respite care	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Legal advice	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Housing assistance	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Employment services	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Return to work skills	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Drug/alcohol treatment	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Mental health services	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Library	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Internet access	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Transport	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Treatments information	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Volunteer carer	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Paid carer	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Internet based information	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Community education campaigns	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation
Other (please specify)	<input type="checkbox"/> HIV/AIDS organisation	<input type="checkbox"/> Other organisation

D33 Are there any services you feel you need but cannot currently get? (please describe)

SECTION E
future 5

This section contains questions about sex and relationships. Because both men and women, straight and gay, are completing the survey, some questions may not apply to you. Remember, you do not have to answer questions if you do not wish to. We'd like you to answer the questions as best you can.

E1 How would you describe your sexuality? (tick one only)

- Gay/homosexual/lesbian Bisexual
 Heterosexual or straight Other (please specify) _____

E2 Please indicate how you feel about the following statements:

	strongly disagree	disagree	agree	strongly agree	don't know
I prefer to have a relationship with someone who also has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Few people would want a relationship with someone who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am afraid of telling potential partners of my HIV status in case they reject me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am afraid of infecting my partner, or potential partner, with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel more confident about unprotected sex because of the new treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I know that my partner is HIV positive I find sex more pleasurable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV has had a negative effect on my sexual pleasure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am concerned about becoming infected with another strain of HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being HIV positive has helped me form more satisfying relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If there was a vaccine which prevents HIV I would not practice safe sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Knowing a vaccine will become available makes me less anxious about sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I stopped having sex because of my HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV has negatively affected my libido	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E3 Which of the following best describes your sexual relationships over the last six months?

- I have no sex at present
 I have casual sex only
 I have a regular relationship with one person, and I have sex with other people
 I have a regular relationship with one person, and I do not have sex with other people
 I have a regular relationship with two or more people

E4 **Are you now in a regular relationship/married?**

- Yes No (*go to E10*)

If you have more than one regular relationship, think about your primary regular partner in answering the following questions

E5 **How long have you been in this relationship?** months years

E6 **What is your partner's HIV status**

- HIV Positive HIV Negative Don't Know

E7 **Have you told your current partner of your HIV status?**

- Yes No (*Go to E10*)

E8 **How far into the relationship did you tell your partner (*tick one only*)**

- They already knew A few months into the relationship
 At the start of the relationship A year or longer into the relationship
 A few days into the relationship When I found out that I was HIV positive
 A few weeks into the relationship

E9 **How did your partner react? (*tick as many as apply*)**

- It did not make any difference We became closer
 They were supportive They were worried/scared
 They were angry

E9a) How did you feel? (*tick as many as apply*)

- It did not make any difference We became closer
 I was relieved I was worried/scared
 I was angry

Answer these questions if you had sex with a regular partner in the last 6 months. If you did not have sex with a regular partner in the last 6 months please go to E14 on page 30.

E10 **In the past 6 months have you had sex - vaginal or anal - with a regular male partner?**

- Yes No (*go to E12*)

E11 **In the past 6 months how often did you use a condom during sex - vaginal or anal - with a regular male partner?**

- Never Sometimes Usually Always

E12 **In the past 6 months have you had sex - vaginal or anal - with a regular female partner?**

- Yes No (*go to E14*)

E13 **In the past 6 months how often did you use a condom during sex - vaginal or anal - with a regular female partner?**

- Never Sometimes Usually Always

Casual Partners

E14 In the past 6 months, have you had sex with any casual partners?

- Yes No (Go to F1 on page 31)

E14a) In the past 6 months, how many of your casual sexual partners have been HIV positive?

- All of them Some of them None of them Not sure

E15 In the past 6 months have you had sex - vaginal or anal - with a casual male partner?

- Yes No (go to E17)

E16 In the past 6 months how often did you use a condom during sex - vaginal or anal - with a casual male partner?

- Never Sometimes Usually Always

E17 In the past 6 months have you had sex - vaginal or anal - with a casual female partner?

- Yes No (go to E19)

E18 In the past 6 months how often did you use a condom during sex - vaginal or anal - with a casual female partner?

- Never Sometimes Usually Always

E19 Thinking about the most recent time in the last 6 months you had sex with a casual partner, what was the sex of your partner?

- Male Female

E20 What was the HIV status of your partner?

- HIV positive HIV-negative Don't know (go to E21)

E20a) How did you know your partner's status? (tick as many as apply)

- They told me I could tell by the sort of sex they wanted
 Someone else told me I could tell by their physical appearance
 I could tell by the people they were with I could tell by the bar/venue where we met
 Other (please specify) _____

E21 Did you tell this person you were HIV positive?

- No Yes They already knew Don't Know/ Can't remember

E22 Did you have sex - vaginal or anal? No (go to section F on the next page) Yes

E23 Were condoms used on this occasion? No Yes

E24 Did your partner ejaculate (cum) inside you? No Yes

**Only men should answer the following question.
 Women please go to Section F, on the next page.**

E25 Did you ejaculate (cum) inside your partner? No Yes

SECTION F

This section deals with employment issues, both for those who are currently in paid work and those who are not currently in paid work.

F1 Which of the following best describes your employment situation? *(tick one box only)*

- Student
- Unemployed
- Not working/Retired
- Home duties
- Work full-time What is your occupation? _____
- Work part-time What is your occupation? _____
- Other *(please specify)* _____

F2 If you are working, how many hours per week do you usually work? hours

F3 If you are not working, how long ago did you stop working? months years

F4 Do you do any volunteer (unpaid) work?

- No
- Yes - for an HIV/AIDS organisation
- Yes - for another organisation

F5 How did finding out you were HIV positive affect your career plans? *(tick one)*

- My career plans did not change
- A career was no longer as important
- I changed careers
- I was less likely to change careers
- It was more difficult to plan for the future
- My career ended/I stopped work

F5a) Since then how has HIV affected your career plans? *(tick one)*

- My career plans have not changed
- A career is no longer as important
- I changed careers
- I am now less likely to change careers
- It is more difficult to plan for the future
- My career ended/I stopped work

F6 How has combination antiretroviral therapy affected your career plans? *(tick one only)*

- I have not used antiretroviral drugs
- There has been no change to my plans
- I considered a new career plan
- I made a new career plan
- I considered stopping work
- I stopped work
- I considered going back to work
- I went back to work
- I anticipate a longer time in the workforce
- Other *(please specify)* _____

F7 **Have you ever experienced less favourable treatment than other people at work as a result of having HIV/AIDS?**

- Yes, in the last 2 years Yes, more than 2 years ago No

Please specify: _____

If you have never been in paid employment please go to F20 on page 34.

F8 **Have you ever stopped work for reasons relating to being HIV positive?**

- Yes No (*go to F14 on page 33*)

F8a) How many times have you stopped work due to HIV?

F8b) When was the last time you stopped working? year:

F8c) How long was this for? months years

F9 **The last time you stopped working, why did you stop working? (*tick as many as apply to you*)**

- Stress, depression, anxiety Redundant/sacked
 Low energy levels Expecting illness in the future
 Poor health To move to a different location
 To have more time to myself Other (*please specify*) _____
 To care for another HIV positive person

F10 **Which of the following describes your HIV/AIDS status the last time you stopped working?**

(*tick one box only*)

- I had HIV but had not been ill
 I had HIV and had been ill
 I had been diagnosed with an AIDS-defining illness

F11 **What was your main source of income the last time you were not working? (*tick one box only*)**

- Salary Partner supported me
 Superannuation/annuity/savings Family/friends supported me
 Benefits/pension/social security Other (*please specify*) _____

F12 **Did you go back to work?**

- Yes No (*go to F20 on page 34*)

F13 **Why did you go back to work? (*tick as many as apply to you*)**

- Financial reasons The possibility of flexible work hours
 To do something worthwhile The possibility of working part-time
 To have something to do The possibility of working full-time
 Better physical health To have more social contact
 Better psychological health Other _____

Only answer these questions if you are currently in paid work.
If you are not currently working go to F20 on page 34.

F14 Is your work HIV/AIDS-related?

- No Yes

F15 How would you describe the level of stress in your job?

- Very low Low Moderate High Very high

F16 How many people at your workplace know you have HIV/AIDS?

- Everyone Most people A few people One person No-one

F17 Do you have any difficulties keeping your HIV status confidential? *(tick as many as apply)*

- I do not try to keep my HIV status confidential
 No problems
 Difficulty keeping and taking medication
 Explaining absences from work
 Visible signs of illness
 Gossip
 Other *(please specify)*
-

F18 How is your capacity to perform your work duties affected by your HIV/AIDS status?

(tick as many as apply)

- It is not affected I tire more quickly
 I cannot always go to work I am less productive
 I work reduced hours I have difficulty concentrating
 I do different duties Other *(please specify)*
-

F19 Does your workplace give you flexibility to take time off work for the following?

	never	seldom	sometimes	often	always
For medical appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When you are sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To do volunteer work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Everyone should answer the questions on this page.

F20 Are you thinking of changing your work arrangements?

- Yes No (Go to F23)

F21 What changes do you want to make? (tick as many as apply)

- | | |
|---|---|
| <input type="checkbox"/> I want to start work/return to work | <input type="checkbox"/> I want to reduce my work hours |
| <input type="checkbox"/> I want to stop work | <input type="checkbox"/> I want to increase my work hours |
| <input type="checkbox"/> I want to change the type of work I do | <input type="checkbox"/> Other (please specify) _____ |

F22 Why are you thinking of changing your work arrangements? (tick as many as apply to you)

- | | |
|--|---|
| <input type="checkbox"/> Financial reasons | <input type="checkbox"/> The possibility of flexible work hours |
| <input type="checkbox"/> To reduce stress | <input type="checkbox"/> The possibility of working part-time |
| <input type="checkbox"/> To do something worthwhile | <input type="checkbox"/> The possibility of working full-time |
| <input type="checkbox"/> To have something to do | <input type="checkbox"/> To have more social contact |
| <input type="checkbox"/> Better physical health | <input type="checkbox"/> To have less social contact |
| <input type="checkbox"/> Worse physical health | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Better psychological health | _____ |
| <input type="checkbox"/> Worse psychological health | _____ |

F23 How do you spend your time (excluding paid work)? (tick the 3 that you spend the most time doing)

- | | |
|--|--|
| <input type="checkbox"/> Resting | <input type="checkbox"/> Socialising with close friends |
| <input type="checkbox"/> Leisure activities (reading, etc.) | <input type="checkbox"/> Socialising with other friends |
| <input type="checkbox"/> Volunteer work in HIV/AIDS organisation | <input type="checkbox"/> Looking after children |
| <input type="checkbox"/> Volunteer work in other organisation | <input type="checkbox"/> Looking after another HIV positive person |
| <input type="checkbox"/> Housework/chores | <input type="checkbox"/> Spending time with family |
| <input type="checkbox"/> Socialising with HIV positive friends | <input type="checkbox"/> Other (please specify) _____ |
| | _____ |
| | _____ |

SECTION G
futures

The following questions are about the use of non-clinical drugs, some of which are illegal. We are interested in the differences in the experience of HIV/AIDS and things like use of services between people who use these drugs and those who don't.

G1 Which of the following have you used in the last 12 months? *(please tick as many as apply)*

- | | | |
|--|---|--|
| <input type="checkbox"/> Alcohol | <input type="checkbox"/> Cocaine (injected) | <input type="checkbox"/> Methadone (prescribed) |
| <input type="checkbox"/> Cigarettes | <input type="checkbox"/> Cocaine (not injected) | <input type="checkbox"/> Methadone (other) |
| <input type="checkbox"/> Marijuana | <input type="checkbox"/> Ecstasy | <input type="checkbox"/> Steroids (injected) |
| <input type="checkbox"/> Speed (injected) | <input type="checkbox"/> LSD/trips | <input type="checkbox"/> GHB/GBH/Fantasy |
| <input type="checkbox"/> Speed (not injected) | <input type="checkbox"/> Amyl | <input type="checkbox"/> Viagra or similar |
| <input type="checkbox"/> Heroin (injected) | <input type="checkbox"/> Homebake | <input type="checkbox"/> Other <i>(please specify)</i> _____ |
| <input type="checkbox"/> Heroin (not injected) | <input type="checkbox"/> Crystal Meth | _____ |
| | | <input type="checkbox"/> None |

G2 Have you ever used illegal drugs?

- Yes No *(Go to G6)*

G3 Have you ever had a bad experience from using both antiretroviral drugs and illegal drugs?

- Yes - *(please specify)* _____
- No N/A I have never taken antiretroviral drugs

G3a) Has use of illegal drugs ever resulted in you missing a dose of antiretroviral drugs?

- No Yes N/A I have never taken antiretroviral drugs

G4 Have you ever injected illegal drugs?

- No, never *(go to G6)* Yes - in the last 12 months
- Yes - more than 12 months ago

G4a) When did you first inject drugs? year

G5 Have you shared injecting equipment in the last 12 months?

- Yes No *(go to G6)*

G5a) The last time you shared injecting equipment which of the following describe the circumstances? *(tick as many as apply)*

- | | |
|--|--|
| <input type="checkbox"/> The person was my sexual partner | <input type="checkbox"/> The person was HIV positive |
| <input type="checkbox"/> The needle was bleached and/or washed | <input type="checkbox"/> The person was Hep C positive |
| <input type="checkbox"/> We did not have access to other needles | <input type="checkbox"/> I used the equipment last |
| <input type="checkbox"/> It was in a group | |

G6 Please indicate how you feel about the following statements:

- | | strongly disagree | disagree | agree | strongly agree | not applicable |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| I drink alcohol more than I would like to. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I use illegal drugs more than I would like to. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sharing needles is not a problem if your viral load is undetectable. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I worry about infecting others by sharing needles. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

SECTION H

futuresfive

This section asks about your financial situation

H1 **What is your main source of income?** *(tick one box only)*

Salary
 Partner supports me
 Superannuation/annuity/savings
 Family/friends support me
 Benefits/pension/social security
 Other *(please specify)* _____

H2 **What is your weekly after-tax (in hand) income?** \$.00

H3 **If you have a partner who provides financial support or who shares financial resources, what is your partner's weekly after-tax (in hand) income?** \$.00

H4 **Do you have private health insurance?** Yes No

H5 **Do you have other income or mortgage insurance?** Yes No

H6 **Do you own your own home or flat?**

Yes
 Currently paying off home/flat
 No

H7 **Have you owned your own home or flat in the past?** Yes No

H8 **Are you currently receiving rental assistance or a rental subsidy?**

Yes, \$ per week
 No

H9 **Have you experienced less favourable treatment in relation to insurance?**

No
 Yes *(please specify)* _____

 Year

H10 **How much do you pay per week in rent or mortgage repayments:** \$.00

H11 **How much do you spend per week on complementary therapies?** \$.00

H12 **How much do you spend per week on antiretroviral drugs?** \$.00

H13 **How much do you spend per week on other medication?** \$.00

H14 **How much do you spend per week on food?** \$.00

H15 **How much do you spend per week on utilities?** \$.00

H16 **How much is your current debt (credit cards, loans etc)?** \$.00

H17 **Have you used the services of a financial counsellor in the last two years**

Yes
 No

H18 **If you have been on either a disability support pension or a sickness benefit in the last 2 years, did you have an assessment from Centrelink?**

- Yes No (*go to H19*)

H18a) Did this experience: (*tick as many as apply*)

- Result in termination of your benefits
- Result in changes to the conditions of your benefits
- Clarify concerns that you had
- Result in an independent assessment
- Result in a shift from Pension to Newstart allowance
- Require documentation from your doctor
- Cause you distress

H19 **In the past 6 months, how difficult has it been for you to meet the costs of the following?**

	not at all difficult	a little difficult	very difficult	doesn't apply
Co-payments for medication for HIV/AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other prescribed medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical services (doctor, dentist, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary Therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support services (counselling, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Entertainment (theatre, movies, concerts, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going out (eating/drinking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sport (exercise, gym, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreational drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel/holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rent/Mortgage/Housing costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Utilities (telephone/electricity/gas/water)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other please specify	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other please specify	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

H20 **Please fill in the date that you completed this survey:** / /

Thank you!

Finally, it would be helpful for us if you could indicate how you found out about this study. If more than one applies, please tick the one which made you decide to participate.

- I completed a previous HIV Futures Survey in 2003, 2001, 1999 or 1997
- Mail-out from HIV/AIDS-related organisation (eg, PLWHA Organisation, AIDS Council)
- Picked up a copy of the survey at an HIV/AIDS-related organisation
- Picked up a copy of the survey at a Medical Centre or Hospital
- Haemophilia Association
- Positive Women's Organisation
- HIV information centre
- Article or advertisement in Positive Living
- Article or advertisement in gay newspaper or magazine
- Article or advertisement in other community press
- Recruited by researcher
- Told about it by someone who had already completed it
- Postcard picked up at HIV/AIDS-related organisation
- Postcard picked up at a Medical Centre or Hospital
- Postcard picked up at gay venue
- Postcard picked up at other location
- Talkabout
- Other (*specify*)

Have you ever completed any of the following surveys:

- | | |
|---|---|
| <input type="checkbox"/> Positive Health (pH) | <input type="checkbox"/> HIV Futures 3 (2001) |
| <input type="checkbox"/> HIV Futures 1 (1997) | <input type="checkbox"/> HIV Futures 4 (2003) |
| <input type="checkbox"/> HIV Futures 2 (1999) | <input type="checkbox"/> Periodic survey |

Are there any other comments you would like to make about your experience of living with HIV or about this survey?

Thank you for taking the time to complete this survey. We appreciate the generosity of HIV positive people who share their experiences to help make things better for all positive people.

We understand that the things covered in this survey may raise questions or uncomfortable issues. If you would like to talk about these with people who are experienced in these matters, please contact one of the organisations listed below.

National

Australian Federation of AIDS Organisations **(02) 9557 9399**

AIVL (Australian Injecting & Illicit Drug Users League) **(02) 6279 1600**

National Association of People Living with HIV/AIDS **(02) 9557 8825 or 1800 259 666**

ACT

AIDS Action Council of the ACT **(02) 6257 2855**

NSW

AIDS Council of NSW **(02) 9206 2000 or 1800 063 060**

Positive Heterosexuals **(02) 1 800 812 404**

NSW HIV Information line **(02) 9332 4000 or 1800 451 600** (outside Sydney Metro area)

PLWHA (NSW) **(02) 9361 6011 or 1800 245 677**

NT

Northern Territory AIDS and Hepatitis Council **(08) 8941 1711 or 1800 880 899**

QLD

Queensland Positive People **(07) 3013 5555 or 1800 636 241** (within Queensland only)

St Lukes Positive Directions **(07) 3421 2841**

SA

AIDS Council of South Australia **(08) 8334 1611 or 1800 888 559**

PLWHA (SA) **(08) 8293 3700**

HIV Women's Project **(08) 8239 9600**

TAS

Tasmanian Council on AIDS Hepatitis & Related Diseases **(03) 6234 1242**

VIC

AIDSline **(03) 9347 6099 or 1800 133 392**

PLWHA (Vic) **(03) 9865 6772**

Positive Women **(03) 9276 6918**

Straight Arrows **(03) 9276 3792**

Victorian AIDS Council/Gay Men's Health Centre **(03) 9865 6700**

WA

The Living Centre **(08) 9470 4931**

Western Australian AIDS Council **(08) 9482 0000**

