

ures futures six

HIV futures six

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, 2003 and 2005 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, and ensure that education and support services for positive people are the most effective they can be.

The results of this survey will go to the community groups who work with positive people. A community report will also be available to everyone and the results will 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), the Australian Federation of AIDS Organisations (AFAO) and the Australasian Society for HIV Medicine (ASHM).

The researchers on this project are Dr Jeffrey Grierson, Senior Research Fellow, Jennifer Power and Rachel Thorpe, Research Officers with the Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe 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 a national program of social research around people living with HIV/AIDS.

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



future**six**

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 twenty years for comparison with future studies.

The survey will take between 40 minutes and 1½ 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 Jennifer Power 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 15 January, 2009

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 Catholic Other Christian
 New Age 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

future

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)*

- | | |
|---|---|
| <input type="checkbox"/> Own or purchasing house or flat | <input type="checkbox"/> Rent-free (e.g. provided by friends, family, etc.) |
| <input type="checkbox"/> Private rental accommodation | <input type="checkbox"/> Community housing/housing co-operative |
| <input type="checkbox"/> Public rental accommodation (government owned) | <input type="checkbox"/> Other <i>(please describe)</i> _____ |

B2 **Who do you live with?** *(tick as many as apply to you)*

- | | |
|---|--|
| <input type="checkbox"/> No-one | <input type="checkbox"/> Other family members |
| <input type="checkbox"/> Partner/spouse | <input type="checkbox"/> Friend(s)/Flatmate(s) |
| <input type="checkbox"/> Dependent children | <input type="checkbox"/> Other <i>(please specify)</i> _____ |

B3 **How many people do you live with** Adults Children

B4 **Do you have any children?** Yes No *(go to B6)*

B5 **Please provide some details**

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

B6 **Have you ever changed your accommodation as a result of having HIV/AIDS?**

- Yes *(go to B7)* No *(go to B8)*

B7 **Number of times ever** **Number of times in last 2 years**

B8 **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

B9 **Do you own, or have access to a car?**

- Yes No

B10 **How easy is it for you to get public transport to and from your home?**

- Very difficult Difficult Easy Very easy

B11 Do you own any pets?

Yes *(please specify number and type, eg. 3 cats and a dog)*

No

B12 Do you do any of the following to improve your health and well being? *(tick all that apply)*

Exercise

Reduce or stop smoking

Spending time with partner

Healthy eating

Relaxation

Spending time with family

Spending time with friends

Spending time with pets

Other *(please specify)*

B13 What is your height?

cm

B14 What is your current weight?

kg

SECTION C

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 <i>(please specify)</i> _____ |
- C5 Did you receive counselling (or a detailed discussion) about HIV before you were tested for HIV?
- Yes No
- C6 Did you receive counselling (or a detailed discussion) about HIV after you tested HIV positive?
- 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"/> Sex with a woman |
| <input type="checkbox"/> Injecting drugs | <input type="checkbox"/> Blood products |
| <input type="checkbox"/> Don't know | |
| <input type="checkbox"/> Other <i>(please specify)</i> _____ | |
- 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 a sexually transmissible infection in the last 12 months?

- No (go to C15) Yes
- Gonorrhoea Chlamydia Genital Herpes
- Syphilis Other (please specify) _____

C15 Have you been diagnosed with any mental health conditions?

Yes No (go to C16)

Depression year

Anxiety year

Other condition, *please specify and where possible include year of diagnosis:*

_____ year

_____ year

T-CELL (CD4) AND VIRAL LOAD TESTING

C16 Have you ever had a T-cell (CD4) test?

Yes No - why not? _____

Don't know

C17 What was the result of your most recent test? cells/ μ L

C18 When was this test? month year

C19 In the past 12 months, has your T-cell (CD4) count:

stayed the same increased gone up and down

decreased don't know

C20 Have you ever had a viral load test?

Yes No - why not? _____

Don't know

C21 What was the result of your most recent viral load test?

Undetectable or copies/mL

C22 When was this test? month year

C23 How many viral load tests have you had in the last 12 months?

C24 In the past 12 months, has your viral load:

stayed the same increased gone up and down

decreased don't know

C25 Have you had a viral resistance test?

Yes No

C25a) When was your last resistance test? month year

C25b) At the time of this test, what was your:

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

C25c) Did this test find resistance to any antiretroviral drug? Yes No

C25d) Did you change treatments as a result of this test? Yes No

C25e) Did your viral load change following this?

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

C25f) Did your CD4 count change following this?

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

C26 Have you ever been vaccinated against hepatitis A?

Yes No

C27 Have you ever had hepatitis A?

Yes No

C28 Have you ever been vaccinated against hepatitis B?

Yes No

C29 Have you ever had hepatitis B?

Yes No

C30 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.

C31 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

C32 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 C33 (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
 Injection Drug Use (IDU)
 Don't know
 Body Piercing
 Tattooing
 Other (please specify)
-

HC4) Have you had a hep C Genotype test?

- Yes
 No

HC4a) What was the result of this test?

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

HC5) Since being diagnosed with hep C, have you ever tested negative on a PCR test?

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

HC6) 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

Ribavirin

(combination

therapy)

- No

- Currently taking it

- Completed treatment,

Year

- Taken previously but not completed

Year

Other treatments (please specify)

HC7) Do you currently see a doctor for hepatitis C treatment/management? (tick one only)

- I do not see a doctor for hepatitis C
 I see a separate hepatitis C doctor/specialist
 I see my primary HIV doctor

The following questions are for everyone

C33 Have you ever had a bone density test

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

C34 Have you ever had a fasting cholesterol test?

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

C35 Have you had a routine sexual health screen (blood or swab tests) in the past 12 months?

- Yes No

C36 In the last 6 months have you taken any medications for anxiety?

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

- Yes No

C37 In the last 6 months have you taken any medications for depression?

(e.g. *Anafranil, Aropax, Aurorix, Avanza, Cipramil, Deptran, Efexor, Lovan, Luvox, Prozac, Sertraline, Tofranil, Tryptanol, Tolvon, Zactin, Zoloft*)

- Yes No

C38 In the last 6 months have you taken any of the following medications for your nerves?

(e.g. *Amisulpride, Clozapine, Haldol, Largactil, Stelazine, Modecate, Risperdal, Serenace, Zyprexa*)

- Yes No

C39 Apart from Antiretroviral therapy and those listed in C36-C38, are you currently taking any prescribed medication (e.g. *contraceptives, Insulin, HRT, prophylaxis*)

- Yes (*please specify*) _____ No

C40 How many times per day do you take:

antiretroviral drugs

complementary therapies

medication for health conditions not related to HIV/AIDS

C41 How many times in total do you have to take medication of any kind per day?

C42 Have you used any of the following therapies over the past 6 months?

- Yes (*tick as many as apply*) No

Vitamin/mineral supplements (*please specify*) _____

Herbal therapies/supplements (*please specify*) _____

Meditation/visualisation

Massage

Acupuncture

Marijuana for therapeutic purposes

Traditional Chinese Medicine

Other complementary or alternative therapies (*please specify*) _____

C43 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 C47 on the next page

C44 Have you ever had a cervical (pap) smear test?

Yes No - why not?

go to C47

C45 Have you had a pap smear test in the last 12 months? Yes No

C46 What was the result of your most recent pap smear test?

- Normal
 - Atypia
 - HPV
 - CIN1/mild dysplasia/low grade abnormality
 - CIN2/moderate dysplasia/high grade abnormality
 - CIN3/severe dysplasia/high grade abnormality
 - Don't know
 - Other
-

Everyone should answer the following questions

By 'antiretroviral drugs' we mean drugs such as: 3TC/Efavirenz, Nevirapine/Viramune, Ritonavir/Norvir, Tenofovir/Viread or Kaletra. When we talk about 'combination therapy', we mean any two or more antiretroviral drugs taken together.

C47 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"/> |
| 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"/> |
| 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"/> |

C48 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

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.

C49 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

If you have never taken antiretroviral drugs please go to C81 on page 17

C50 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 C65 on page 15. If you are currently using antiretroviral drugs, please continue

C51 How long have you been using antiretroviral drugs? days months years

C52 Which of the following drugs are you currently using? (tick as many as apply)

- | | |
|---|--|
| <input type="checkbox"/> Abacavir (Ziagen) | <input type="checkbox"/> Interleukin-2 (IL-2) |
| <input type="checkbox"/> Amprenavir (Agenerase) | <input type="checkbox"/> Kaletra (Lopinavir & Ritonavir) |
| <input type="checkbox"/> Atazanavir (Reyataz) | <input type="checkbox"/> Kivexa (Abacavir & 3TC) |
| <input type="checkbox"/> AZT (Zidovudine, Retrovir) | <input type="checkbox"/> Nelfinavir (Viracept) |
| <input type="checkbox"/> 3TC (Lamivudine) | <input type="checkbox"/> Nevirapine (Viramune) |
| <input type="checkbox"/> Combivir (AZT & 3TC) | <input type="checkbox"/> Ritonavir (Norvir) |
| <input type="checkbox"/> ddC (Zalcitabine, Hivid) | <input type="checkbox"/> Saquinavir (Invirase) |
| <input type="checkbox"/> ddI (Didanosine, Videx/Videx EC) | <input type="checkbox"/> T-20 (Enfurvitide, Fuzeon) |
| <input type="checkbox"/> d4T (Stavudine, Zerit) | <input type="checkbox"/> Tenofovir (Viread) |
| <input type="checkbox"/> Delavirdine (Rescriptor) | <input type="checkbox"/> Tipranavir (Aptivus) |
| <input type="checkbox"/> Efavirenz (Stocrin) | <input type="checkbox"/> Trizivir (Abacavir & AZT & 3TC) |
| <input type="checkbox"/> Indinavir (Crixivan) | <input type="checkbox"/> Other (please specify) |
-

C53 For what period does your antiretroviral prescription usually last?

weeks months

C54 Who prescribes your antiretroviral drugs? (tick as many as apply)

- | | |
|--|--|
| <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"/> HIV specialist while an inpatient at hospital |
| <input type="checkbox"/> Other (please specify) | |
-

C55 Do you experience any difficulties in taking antiretroviral drugs?

C55a Yes (tick as many as apply) No (go to C56)

- 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)

C56 Since you started taking antiretroviral drugs has your physical health
 stayed the same improved fluctuated deteriorated

C57 Since you started taking antiretroviral drugs has your overall feeling of well-being:
 stayed the same improved fluctuated deteriorated

C58 Since beginning antiretroviral therapy, approximately how many different combinations of drugs have you used?

C59 In the past 12 months, how many different combinations of antiretroviral drugs have you used?

C60 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

C61 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"/> |

C62 How many doses (dose times) of antiretroviral drugs did you miss yesterday?
 None One Two Three Four Five or more

C63 How many doses (dose times) of antiretroviral drugs did you miss the day before yesterday?
 None One Two Three Four Five or more

C64 Have you ever taken a break from your antiretroviral treatments (had a drug holiday)?
 Yes (go to C71 on page 16) No (go to Section D p18)

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

C65 Are you currently on a treatment break/planning to use antiretroviral drugs again in the future?
 Yes (go to C71 on page 16) No (continue)

C66 How long did you use these drugs for? days months years

C67 When did you stop using these drugs? days months years

C68 When you decided to stop using antiretroviral drugs, how many antiretroviral drugs were you using?

C69 **Why did you stop taking antiretroviral drugs?** (*tick as many as apply to you*)

- Side effects Difficulty carrying/transporting medication
 Taking part in a clinical trial Difficulty organising meals around medication
 Recommended by my doctor Difficulty taking a large number of tablets
 Difficulty taking medication in public
 Other (*please specify*) _____

C70 **Did you talk to your HIV doctor about this before stopping treatment?**

- Yes No

Answer this section if you have ever taken a treatment break (had a drug holiday). If you have never taken a treatment break go to section D on page 18.

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

C71 **When did you start the treatment break?** month year

C72 **How long was the break?** days months I am still on the break

C73 **What type of break was this?** (*tick one box only*)

- Structured Treatment Interruption Treatment Break
 Other (*please specify*) _____

C74 **Just before taking this break, what was your:**

T-cell (CD4) count cells/ μ L

Viral load Undetectable or copies/mL

C75 **Did you have lifestyle (non-medical) reasons for taking a treatment break the last time you did so?**

- Yes No (*go to C76*)

C75a What were these reasons? (*tick as many as apply*)

- It didn't fit my lifestyle
 The financial burden became too heavy
 A special event
 Taking drugs at the right time was too difficult
 Clean out my system
 Travel
 Other (*please specify*) _____

C76 Did you have clinical reasons for taking a treatment break the last time you did so?

- Yes No (go to C77)

C76a What were these reasons? (tick as many as apply)

- Drug resistance developed Recommended by my doctor
 Side effects became too severe Recommended by other health professional
 Changing regimens Liver toxicity problems
 Complications with Hep C Taking part in a clinical trial
 Other (please specify)
-

C77 Did you talk to your HIV doctor about this before taking this break?

- Yes No

C78 Did you talk to your HIV doctor about this while taking this break?

- Yes No

C79 Did you talk to your HIV doctor about this after taking this break?

- Yes No

C80 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

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

C81 Would you consider using antiretroviral drugs at any time in the future?

- Yes No C81a) Why not?
-
-

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.

D1 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"/> Heroin (injected) | <input type="checkbox"/> Steroids (injected) |
| <input type="checkbox"/> Cigarettes | <input type="checkbox"/> Cocaine (not injected) | <input type="checkbox"/> GHB/GBH/Fantasy |
| <input type="checkbox"/> Marijuana | <input type="checkbox"/> Ecstasy | <input type="checkbox"/> Viagra or similar |
| <input type="checkbox"/> Crystal Meth | <input type="checkbox"/> LSD/trips | <input type="checkbox"/> Speed (not injected) |
| <input type="checkbox"/> Amyl | <input type="checkbox"/> Speed (injected) | <input type="checkbox"/> None |
| <input type="checkbox"/> Methadone (prescribed) | | |
| <input type="checkbox"/> Other <i>(please specify)</i> | | |
-

D2 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 *(go to E1)*

N/A I have never used illegal drugs *(go to E1)*

D2a) Has use of illegal drugs ever resulted in you missing a dose of antiretroviral drugs?

Yes No

N/A I have never taken antiretroviral drugs

N/A I have never used illegal drugs

SECTION E

future six

This section deals with the ways in which positive people interact with services and communities

E1 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"/> | <input type="checkbox"/> |
| AIDS Council staff (others) | <input type="checkbox"/> | <input type="checkbox"/> |
| PLWHA Organisation staff (treatments-specific) | <input type="checkbox"/> | <input type="checkbox"/> |
| PLWHA Organisation staff (others) | <input type="checkbox"/> | <input type="checkbox"/> |
| Peer support officer | <input type="checkbox"/> | <input type="checkbox"/> |
| Positive Women's Organisation | <input type="checkbox"/> | <input type="checkbox"/> |
| Positive Heterosexuals Organisation | <input type="checkbox"/> | <input type="checkbox"/> |
| Other HIV/AIDS Organisation staff | <input type="checkbox"/> | <input type="checkbox"/> |
| HIV GP/S100 Prescriber | <input type="checkbox"/> | <input type="checkbox"/> |
| Other GP | <input type="checkbox"/> | <input type="checkbox"/> |
| HIV specialist | <input type="checkbox"/> | <input type="checkbox"/> |
| Sexual Health Service | <input type="checkbox"/> | <input type="checkbox"/> |
| Nurse | <input type="checkbox"/> | <input type="checkbox"/> |
| Pharmacist | <input type="checkbox"/> | <input type="checkbox"/> |
| Dentist | <input type="checkbox"/> | <input type="checkbox"/> |
| Dietician | <input type="checkbox"/> | <input type="checkbox"/> |
| Complementary therapist | <input type="checkbox"/> | <input type="checkbox"/> |
| Sex worker Organisation | <input type="checkbox"/> | <input type="checkbox"/> |
| Publications from HIV/AIDS groups | <input type="checkbox"/> | <input type="checkbox"/> |
| HIV magazine/newspaper | <input type="checkbox"/> | <input type="checkbox"/> |
| Articles in gay press | <input type="checkbox"/> | <input type="checkbox"/> |
| Publications from other sources | <input type="checkbox"/> | <input type="checkbox"/> |
| Internet | <input type="checkbox"/> | <input type="checkbox"/> |
| HIV positive friends | <input type="checkbox"/> | <input type="checkbox"/> |
| Partner/lover | <input type="checkbox"/> | <input type="checkbox"/> |
| Family | <input type="checkbox"/> | <input type="checkbox"/> |
| Aboriginal Health Worker | <input type="checkbox"/> | <input type="checkbox"/> |
| Multicultural/CALD HIV/AIDS Service | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (<i>please specify</i>) | <input type="checkbox"/> | <input type="checkbox"/> |

E2 From the list above, select your most important source of information about HIV/AIDS treatments and/or health management.

E3 From the list above, select your most important source of information about living with HIV/AIDS.

E4 **Does lack of information make it difficult for you to make decisions about any of the following?**

Yes (*tick as many as apply*) No (*go to E5*)

- | | |
|--|--|
| <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>) _____ |

E5 **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 | <input type="checkbox"/> Other (<i>please specify</i>) _____ |

E6 **Does this doctor know your HIV status?** Yes No

E7 **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 E5 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 | |
| <input type="checkbox"/> Other (<i>please specify</i>) _____ | |

E8 **Do you have a Medicare card?**

- Yes No, I am ineligible No, other _____

E9 **Have you ever experienced less favourable treatment than other people at medical services as a result of having HIV/AIDS?**

- Yes, in the last 2 years Yes, more than 2 years ago No (*go to E10*)

E9a What form did this less favourable treatment take (*tick all that apply*)

- | | |
|---|--|
| <input type="checkbox"/> Harassment | <input type="checkbox"/> Refusal of treatment |
| <input type="checkbox"/> Avoidance | <input type="checkbox"/> Additional infection control measures |
| <input type="checkbox"/> Being rushed through | <input type="checkbox"/> Confidentiality problems |
| <input type="checkbox"/> Being treated last | <input type="checkbox"/> Other (<i>please specify</i>) _____ |
| <input type="checkbox"/> Abuse | |

E10 **Which publications containing HIV information do you read? (*tick as many as apply to you*)**

- | | | |
|--|---|---|
| <input type="checkbox"/> HIV Australia | <input type="checkbox"/> Talkabout | <input type="checkbox"/> Gay newspapers |
| <input type="checkbox"/> Positive Living (National) | <input type="checkbox"/> SPIN | <input type="checkbox"/> Gay magazines |
| <input type="checkbox"/> Positive Life (PL) (WA) | <input type="checkbox"/> User's News | <input type="checkbox"/> QPP Alive |
| <input type="checkbox"/> National Haemophilia | <input type="checkbox"/> Newsletters from community organisations | |
| <input type="checkbox"/> Overseas magazines (e.g. Poz) | <input type="checkbox"/> Other (<i>please specify</i>) _____ | |

E11 **Have you been involved in a clinical trial for HIV related treatment in the last 2 years?**

Yes No

E12 **Who have you told about your HIV status? (tick as many as apply to you)**

No-one Parents
 Partner/Spouse Brothers and/or sisters
 Positive friends Neighbours
 Close friends People from my ethnic community/group
 Other friends Work colleagues
 Son/daughter - how old were they when you told them?
 years years years years

E13 **Has your HIV status been disclosed to other people when you did not want it to be?**

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

E13a) Who disclosed your status? (tick all that apply)

Partner/Spouse HIV positive friends
 Parents Close friends
 Brothers and/or sisters Other friends
 Son/daughter People from my ethnic community
 Other family Neighbours
 Work colleagues Worker in a health care setting
 Community organisation staff/volunteers
 Other (please specify) _____

E13b) Did this disclosure have a negative effect on you?

Yes No

E14 **Do you personally know any other people who are HIV positive? (tick as many as apply to you)**

No-one Son/daughter
 Partner/Spouse Other relative
 Former partner/Spouse Acquaintance/member of support group
 Friend Other (please specify) _____

E15 **Have you been involved with the care or nursing of a person with HIV/AIDS in the last 2 years?**

Yes No

E16 **Has anyone close to you ever died of AIDS? (tick as many as apply)**

No-one Son/daughter
 Partner/Spouse Other relative
 Former partner/Spouse Acquaintance
 Friend Member of support group

E17 **How much of your free time is spent with other HIV positive people?**

- None A little Some A lot

E18 **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*)
-

E19 **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

E20 **Has this changed in the last two years?**

- Yes No

E21 **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"/> |

E22 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 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 advise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

E23 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"/> |
| 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"/> |
| 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"/> |
| 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"/> |

E24 Do you have contact with any HIV/AIDS-related organisations?

Yes No (go to E27)

E25 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

E26 Which HIV/AIDS organisation(s) do you have contact with?

E27 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 (<i>please specify</i>) | <input type="checkbox"/> HIV/AIDS organisation | <input type="checkbox"/> Other organisation |

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. Remember that you can call us for assistance: **1800 064 398** (free call)

F1 **How would you describe your sexuality?** *(tick one only)*

Gay/homosexual/lesbian

Bisexual

Heterosexual or straight

Other *(please specify)* _____

F2 **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 (sex drive) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am worried about disclosing my HIV status to sexual partners because of the current legal situation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am worried about disclosing my sexual practice to service providers because of the current legal situation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

F3 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

F4 Are you now in a regular relationship/married?

- Yes
- No (go to F8 below)

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

F5 How long have you been in this relationship? months years

F6 What is your partner's HIV status

- HIV Positive
- HIV Negative
- Don't Know

F7 Have you told your current partner of your HIV status?

- Yes
- No

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 F12

F8 In the past 6 months have you had sex - vaginal or anal - with a regular male partner?

- Yes
- No (go to F10)

F9 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

F10 In the past 6 months have you had sex - vaginal or anal - with a regular female partner?

- Yes
- No (go to F12)

F11 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

F12 In the past 6 months, have you had sex with any casual partners?

- Yes No (go to G1)

F13 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

F14 In the past 6 months have you had sex - vaginal or anal - with a casual male partner?

- Yes No (go to F16)

F15 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

F16 In the past 6 months have you had sex - vaginal or anal - with a casual female partner?

- Yes No (go to F18)

F17 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

Most Recent Sexual Partner

F18 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

F19 What was the HIV status of your partner?

- Don't know HIV positive HIV-negative

F20 Did you tell this person you were HIV positive?

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

F21 **Did you have sex - vaginal or anal?**

Yes No *(go to section G)*

F22 **Were condoms used on this occasion?**

Yes No

F23 **Did your partner ejaculate (cum) inside you?**

Yes No

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

F24 **Did you ejaculate (cum) inside your partner?**

Yes No N/A

SECTION G

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

G1 Which of the following best describes your employment situation? *(tick one box only)*

Student

Unemployed

Home duties

Not working/Retired

Work full-time - What is your occupation? _____

Work part-time - What is your occupation? _____

Other *(please specify)* _____

G2 If you are working, how many hours per week do you usually work? hours

G3 If you are not working, how long ago did you stop working? months years

G4 Do you do any volunteer (unpaid) work?

Yes - for an HIV/AIDS organisation

Yes - for another organisation

No

G5 How did finding out you were HIV positive affect your career plans? *(tick one)*

My career plans did not change

I was less likely to change careers

A career was no longer as important

It was more difficult to plan for the future

I changed careers

My career ended/I stopped work

G6 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) _____

**Only answer these questions if you are currently in paid work.
If you are not currently working go to Section H**

G7 **Is your work HIV/AIDS-related?**

- Yes No

G8 **How would you describe the level of stress in your job?**

- Very low Low Moderate High Very high

G9 **How many people at your workplace know you have HIV/AIDS?**

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

G10 **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)
-

G11 **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)
-

G12 **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"/> |

SECTION H

This section asks about your financial situation.

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

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

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

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? \$

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
- No
- Currently paying off home/flat

H7 Are you currently receiving rental assistance or a rental subsidy?

- Yes
- No
- \$ per week

H8 Have you experienced less favourable treatment in relation to insurance?

- Yes *(please specify)* _____
- No

H9 How much do you pay per week in rent or mortgage repayments? \$

H10 How much do you spend per week on complementary therapies? \$

H11 How much do you spend per week on antiretroviral drugs? \$

H12 How much do you spend per week on other medication? \$

H13 How much do you spend per week on food? \$

H14 How much do you spend per week on utilities? \$

H15 How much is your current debt (credit cards, loans etc)? \$

H16 **Have you used the services of a financial counsellor in the last two years?**

Yes No

H17 **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 H18)

H17a) 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

H18 **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"/> |

H19 **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 2005, 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
 - Other (*specify*)
-

Have you ever completed any of the following surveys:

- Positive Health (pH)
- HIV Futures 1 (1997)
- HIV Futures 2 (1999)
- HIV Futures 3 (2001)
- HIV Futures 4 (2003)
- HIV Futures 5 (2005)
- 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) 8568 0300 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 9700 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)

SPIRITUS positive directions **(07) 3900 8000**

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 for AIDS & Related Diseases **(03) 6234 1242**

VIC

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

Positive Women **(03) 9076 6918**

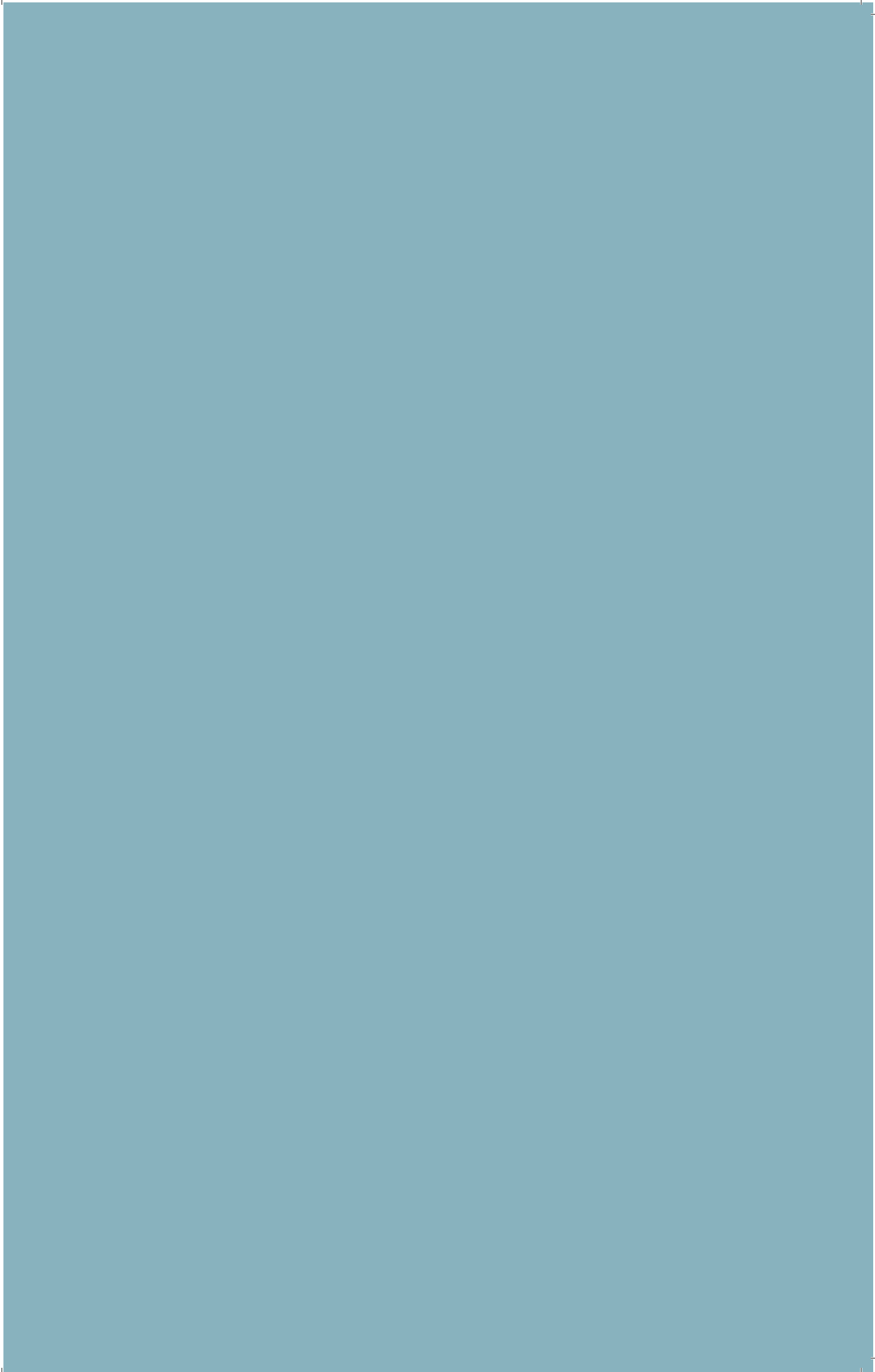
Straight Arrows **(03) 9276 3792**

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**



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