

HIV FUTURES II

Aboriginal and Torres Strait Islander people living with HIV

Jon Willis, Karalyn McDonald, Mark Saunders and Jeffrey Grierson

March 2002

Monograph Series Number 30
ISBN 1920697020

COVER ART

Desert tracks to setting sun
by Gavin Condren

When I was asked to indigenise a pyramid shaped logo for the Australian Research Centre in Sex, Health and Society (La Trobe University) I thought of the lines as travel lines for people travelling to places of healing and learning, to places where there are medicinal plants and of men's and women's places and of the dreamtime.

For this design I have taken my inspiration from the desert. I looked at the point in the left hand corner as a place of healing. So we see red as being blood, symbolic of all Indigenous people. Black comes into play here as representing all Aboriginal and Islander peoples' skin colouring. Black dots represent communities all linked up by travel lines through the orange and red ochre coloured desert to the setting sun the sign of hope of a new day. White dots represent the white man's travel lines that we take nowadays along with the traditional travel lives towards healing and learning for better health.

Yellow is the setting sun: this gives hope, reaching up for a new day
Black dots: represent all Indigenous communities
Orange and red ochre: represents desert sands
Red background: being blood of all Indigenous people
White dots: represent white man's travel lines

A collaborating centre to the National Centre in HIV Social Research

Funded through a CARG Collaborating Centre Grant from the Commonwealth Department of Health and Ageing

Suggested Citation

Willis, J., McDonald, K., Saunders, M. and Grierson, J. (2002) *HIV Futures II: Aboriginal and Torres Strait Islander People Living with HIV*, Monograph Series Number 30, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia.

The Living with HIV Program can be contacted at

**The Australian Research Centre in Sex, Health and Society,
La Trobe University
215 Franklin Street
Melbourne 3000
Australia**

**Phone: +61 3 9285 5382
Email: hivfutures@latrobe.edu.au**

HIV Futures I and II community reports can be found on the HIV Futures website:
www.latrobe.edu.au/hiv-futures

ACKNOWLEDGEMENTS

Nine hundred and twenty-four people living with HIV/AIDS completed the HIV Futures II Survey. We are grateful for their interest in research conducted by the Australian Research Centre in Sex, Health & Society, and thank them for their willingness to participate.

We wish to thank the National Association of People Living with HIV/AIDS (NAPWA), the Australian Federation of AIDS Organisations (AFAO), the Haemophilia Foundation of Australia and its State affiliates.

We would like to express our appreciation and gratitude to the Indigenous Project Steering Committee of the Australian Federation of AIDS Councils and its Chairperson, Robert Smith for their advice on and support for the publication of an Aboriginal and Torres Strait Islander specific report, and to Karen Adams for her comments and advice on the draft report.

In New South Wales distribution of the survey was assisted by the AIDS Council of New South Wales (ACON), Mark Bebbington and Brent Allen at ACON, ACON Community Support Network, ACON Women's project, ACON Hunter, ACON Illawarra, ACON Northern Rivers, ACON Western Sydney, Albion Street Centre, Bigge Park Centre, Blue Mountains PLWHA Centre, Bobby Goldsmith Foundation, Coffs Harbour Sexual Health Centre - Ralph Waldsax, Foley House, Gender Centre, Grafton Community Health Centre, Kempsey Community Health Centre, Karumah Day Centre, Livingstone Road Clinic, Luncheon Club AIDS Support Group, Macquarie Area Health Service, Mid North Coast Area Health Service - Robert Baldwin, Moruya Community Health Centre, New England Area Health Service, New South Wales Department of Health, New South Wales Users and AIDS Association (NUAA), North AIDS, Options Employment Service, Parramatta Sexual Health Centre, Positive Living Centre, People Living with HIV/AIDS - PLWHA (NSW), Pozhet West, Positive Employment Service, Positive Heterosexuals - David Barton, St George Sexual Health Centre, SMASH Project, Sydney PLWHA Day Centre, Talkabout, Wentworth Area Health Service, Wollongong HIV Prevention Service, Peter de Ruyter, and Paul Burr.

Thanks are due to the following individuals and organisations who helped distribute the survey in Victoria: Access Information Centre, AIDS Care Association, ALSO Foundation, Barkly Street Medical Clinic, Country AIDS Network Resource Centre, Melbourne Sexual Health Centre, Mountfield Clinic, People Living with HIV/AIDS - PLWHA (Vic), Stephanie Moore and Positive Women (Vic), Prostitutes' Collective Victoria, Royal Melbourne Hospital HIV Services, Straight Arrows, Victorian AIDS Council (VAC), Jim Arachne at VAC, VIVAIDS, Mattie Sempert, Lisa McPherson, Dr Ralph Ballard and Vincent Boyd.

A number of organisations and individuals aided distribution of the survey in Queensland. Thanks to the AIDS Medical Unit, Brisbane Sexual Health Clinic, Brunswick Street Medical Centre, Gladstone Road Medical Centre, Nambour Hospital, Queensland Positive People (QPP), Simon O'Connor at QPP, QPP Bundaberg, QPP Gold Coast, QPP Mackay, QPP Rockhampton, QPP Sunshine Coast, the Queensland AIDS Council (QAC), QAC Cairns, and QAC Townsville.

In South Australia we were assisted by the Adelaide Diocesan AIDS Council, AIDS Council of South Australia (ACSA), HIV/AIDS Programs - South Australian Health Commission, HIV/AIDS Women's Project, Infectious Diseases Unit - Royal Adelaide Hospital, People Living with HIV/AIDS - PLWHA (SA), and Peter Evans at PLWHA (SA).

A number of organisations and individuals aided distribution of the survey in Western Australia. Thanks to AIDS Pastoral Care, Lindisfarne Medical Group, Social Work Department - Royal Perth Hospital, Western Australian AIDS Council (WAAC), Mark Reid at WAAC, WAAC Women's Project, Trudy Matthews, and Dr Ric Chaney.

Thanks are due to the following individuals and organisations who helped distribute the survey in Tasmania: HIV/AIDS Unit Tasmanian Health Department, Royal Hobart Hospital, Rose Cottage, the Tasmanian Council on AIDS and Related Diseases (TasCARD), and Marilyn Marks at TasCARD.

In the Australian Capital Territory we were assisted by the AIDS Action Council (AACACT), Infectious Diseases Unit - Canberra Hospital, Interchange General Practice, and People Living with HIV/AIDS - PLWHA (ACT).

We are grateful for the assistance of the following individuals and organisations who helped distribute the survey in the Northern Territory: Northern Territory AIDS Council (NTAC), Bill McMahon at NTAC, AIDS Council of Central Australia (ACOCA), Alice Springs Therapeutic Health Centre, Alice Springs Health and Relaxation Centre, Miranda Coates, and Anna Gray.

We would like to express our appreciation for the support of the founding director of the Australian Research Centre in Sex, Health and Society (ARCSHS), Professor Doreen Rosenthal, the acting director of ARCSHS, Professor Gary Dowsett, and the input and assistance of the staff of ARCSHS. We would particularly like to thank the community liaison officers, Anne Mitchell, Jenny Walsh and Philomena Horsley for their invaluable assistance throughout the project. Thanks also to Belinda La Rocca for the data entry.

We are grateful for the advice and assistance provided by Professor Fiona Judd of the Royal Melbourne Hospital around mental health issues and that of Dr Mary O'Brien of ARCSHS around recreational drug issues. Thanks also to Tony Maynard of VAC for advice on treatment issues.

We would like to thank our funding agencies, the Commonwealth Department of Health and Ageing, who fund the Living with HIV Program and the Victorian Health Promotion Foundation (VicHealth) who provide funding for the Australian Research Centre in Sex, Health and Society.

We would like to express our appreciation for the input and advice provided by the members of the HIV Futures II reference group: Jim Arachne, John Paten, Graham Norton, Colin Batrouny, Brent Allen, Michelle Humphreys, John Daye and Phillip Medcalf.

This report arose out of the original HIV Futures Study conducted in 1997 and we would like to acknowledge the researchers on that project, Doug Ezzy, Richard de Visser, Michael Bartos, Karalyn McDonald, Darryl O'Donnell and Doreen Rosenthal.

INTRODUCTION

The HIV Futures Study is designed to provide HIV, health and funding agencies, as well as people and communities affected by HIV with a picture of the overall situation of people living with HIV/AIDS (PLWHA) in Australia. This report provides details about Aboriginal and Torres Strait Islander Australians living with HIV who filled in and returned questionnaires as part of the HIV Futures II survey.

The HIV Futures II survey was conducted by the Living with HIV research program at the Australian Research Centre in Sex, Health and Society, La Trobe University, in the second half of 1999. The survey asked PLWHA about their health, use of antiretroviral and complementary treatments, use of information and support services, and their housing and financial situation. It also asked about sex and relationships, people's social supports, recreational drug use, work situation and future planning.

HIV Futures II is the second time this national survey has been conducted. The research team held consultations with PLWHA and HIV organisations around the country in order to improve this follow-up survey and address new and emerging issues.

The survey was completed by 924 PLWHA from all States and Territories in Australia who represent over 8% of the current population of PLWHA in Australia, as estimated by the National Centre in HIV Epidemiology and Clinical Research (NCHECR, 1999).

The results of this study have been reported in the document *HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia*. The HIV Futures Community Report contains a vast amount of information about the social impacts of HIV/AIDS including: treatment uptake and health management; the impact of HIV/AIDS on sexual practice; the involvement of respondents in community organisations, and the importance of HIV/AIDS organisations to PLWHA; the impact of HIV/AIDS on work and employment participation; and the financial impact of living with HIV/AIDS. In addition to the main community report, and this report on Aboriginal and Torres Strait Islander people living with HIV, data from the Futures II survey has informed reports on women, heterosexual men, people with haemophilia, people coinfecting with hepatitis C and state-based reports.

Of the total sample of PLWHA the majority (90.0%) of respondents were male, 9.7% were female, and 0.3% were transgendered people. Respondents' ages ranged from 18 to 75 years (median = 41.0 years, mean = 42.1 years). Respondents' ages at the time of diagnosis with HIV ranged from 9 to 69 years (median = 32.0 years, mean = 33.2 years).

Of the 924 PLWHA, 77.6% said they are homosexual, 15.5% are heterosexual, 6.2% are bisexual, and 0.6% did not indicate their sexual orientation. Both men and women are represented in each of these categories. Unlike the main community report for HIV

Futures II where data were weighted so that sample demographics matched those of the *Australian HIV Surveillance Report* (NCHECR, 1999) according to gender, state of residence, mode of infection, and diagnosis of an AIDS-defining illness, data in this report were not weighted.

An important warning

We believe that the results presented in this report are a unique snapshot of the experience of living with HIV for the Aboriginal and Torres Strait Islander men and women who responded, but they should be read with some caution. Particularly we warn against using these results to draw general conclusions about the experience of all Aboriginal and Torres Strait Islander people living with HIV. There are four main issues about our methodology to consider here. Firstly, although we asked respondents to indicate whether they identify as an Aboriginal or Torres Strait Islander person, not all of our Indigenous respondents may have chosen to identify themselves in this way.

A second issue is that the total number of Aboriginal and Torres Strait Islander responses to the survey is very small, even though they represent a substantial proportion of the Aboriginal and Torres Strait Islander people who were diagnosed with HIV in the period 1992-1999. Because both our sample and the population it is drawn from are very small, we have tried as far as possible to show actual numbers of responses, rather than percentages or proportions. In some cases, this has meant that we did not report some data, because of the possibility that individual people could be identified from it. In other places, it has meant that we have not compared the Indigenous results with those from the broader population because such comparisons could mislead by implicitly overstating the representativeness of our Indigenous sample.

Thirdly, the questionnaire was designed for the broad community of HIV positive people in Australia, and so does not explore issues about living with HIV that are distinctive for Aboriginal and Torres Strait Islander people. We are cautious about this because although there is not much publicly available information about Indigenous Australians and HIV, this limited information suggests that Aboriginal and Torres Strait Islander people are subject to a range of unique social, cultural and historical factors that impact on how they experience life with HIV, for example use of traditional bush medicines. In this regard, we recognise that although surveys are good instruments for understanding broad social and cultural patterns in relatively homogeneous populations, they may not adequately represent qualitative differences where there is considerable diversity in lived experience.

Finally, the questionnaires were distributed in a way that ensured a generally representative sample of the broad HIV positive community, but did not specifically target Indigenous Australians. Because we currently have no reliable measures of the extent to which Aboriginal and Torres Strait Islander people living with HIV engage with

the general positive community or make use of mainstream HIV services, we simply cannot say whether our distribution strategy ensured that Aboriginal and Torres Strait Islander people living with HIV had the same chance of accessing a copy of the questionnaire as other positive people.

Ethical considerations

The HIV Futures II study was not designed specifically to collect information from Aboriginal and Torres Strait Islander people, and consequently was not subjected to separate ethical scrutiny by an Indigenous ethics committee. However the study was developed in consultation with a HIV positive community reference group, and underwent a rigorous ethics process at La Trobe University that considered the sensitive nature of the questions being asked and conformed to the standards established for studies with human subjects by the National Health and Medical Research Council. Prior to the release of this report, a draft was circulated to a small number of Indigenous researchers for review, and advice about the publication of Indigenous specific data sought and received from the Indigenous Project Steering Committee of the Australian Federation of AIDS Organisations. Reviewers were particularly asked to indicate whether data in the draft report contributed to the stigmatisation of Aboriginal and Torres Strait Islander people in general and within the HIV positive community, and where such stigmatisation was indicated the data were withdrawn. Finally, the survey was an anonymous, self complete, mail back questionnaire and participants indicated their informed consent for their data to be made public by completing and returning the questionnaire.

The people who completed the survey

Of the 924 PLWHA who completed the survey, 23 identified as Aboriginal or Torres Strait Islander people. There are no available statistics of how many Aboriginal and Torres Strait Islander people overall are living with HIV, and so we are unable to say what proportion of these is represented by our sample. Notification statistics suggest that up until the end of 1996, 128 notifications of HIV had been recorded where Indigenous status was recorded, and that 34 Indigenous people with AIDS had died (ANCARD Working Party on Indigenous Australians' Sexual Health, 1997). Since 1996, a further 61 cases among Indigenous people were notified to the end of 2000, although statistics about the number of deaths among Indigenous PLWHA are not publically available (NCHECR, 2001). There are obvious problems with these notification data, not the least of which is that most states and territories have not systematically recorded Indigenous status as part of the notification process. However, we know that our sample is equivalent to 14.8% of the 155 Aboriginal or Torres Strait Islander people whose HIV infection has been notified HIV in Australia to the end of 2000, but whose deaths have not been publically notified (NCHECR, 2001).

Of the 23 Aboriginal and Torres Strait Islander respondents, 18 identified as male and four as female. One respondent did not identify their sex. Around half (12) of the Aboriginal and Torres Strait Islander respondents identified as gay or lesbian, 5 as heterosexual or straight and 6 as bisexual.

The ages of Aboriginal and Torres Strait Islander respondents ranged from 30 to 59, with an average of 37.9 years. Their average age was younger than the rest of the sample (37.9 versus 42.4). Aboriginal and Torres Strait Islander respondents' ages at the time of testing HIV seropositive ranged from 19 to 56, with an average of 27.9 years. Once again Aboriginal and Torres Strait Islander respondents were on average younger than the rest of the sample when they tested HIV seropositive (27.9 versus 33.6).

Most Aboriginal and Torres Strait Islander respondents indicated that they believe they were infected with HIV through sexual contact: ten of the men cited homosexual contact and three men cited homosexual contact and injecting drug use as the likely transmission route. Seven people including the four women respondents cited heterosexual contact. Three people did not indicate how they believe they were infected with HIV.

Of the 23 Aboriginal and Torres Strait Islander respondents who completed the survey, 14 are from New South Wales, 4 from Queensland, 3 from Victoria, 1 from South Australia, and 1 from Western Australia. When asked to describe where they live, 8 reported that they live in a capital city or inner urban area, 8 live in an outer suburban area, 4 live in a regional centre, and 4 live in a rural area.

Of the 23 Aboriginal and Torres Strait Islander respondents one third (8) were on the mailing list for the survey from the first HIV Futures Survey and 5 received their copy of the survey from either a mail out or pick up from an AIDS Council or from a PLWHA organisation. Seven respondents received their survey through personal contacts, either with the researchers (4) or from another person living with HIV (3).

MAJOR FINDINGS

The results reported below compare Aboriginal and Torres Strait Islander people living with HIV with non-Indigenous PLWHA, ie the rest of the sample minus the Aboriginal and Torres Strait Islander respondents

Health and HIV

Respondents were asked about their sense of well-being and general health as well as the effects of HIV. We found that while many Aboriginal and Torres Strait Islander respondents are living with HIV related illness or other major health concerns, around two thirds (15) feel good about their general health and most are actively doing things to improve their health. These include a good diet (18), relaxation (17), taking pills on time (16), exercise (16) and getting adequate sleep (13).

Four Aboriginal and Torres Strait Islander respondents have been diagnosed with an AIDS defining illness at some point, but this has happened less in the last two years. This suggests that antiretroviral treatments have been successful in slowing the progression to AIDS in many people. Four Aboriginal and Torres Strait Islander respondents also reported having experienced an illness or condition related to HIV. These illnesses include oral hairy leukoplakia, chronic diarrhoea, wasting/weight loss, candida, vaginal thrush and cervical dysplasia (one case of each was reported). More than half the respondents also reported disorders relating to HIV medications including lipodystrophy (3), weight loss (12), sleep disorder (15), and memory loss or confusion (12). Five Aboriginal and Torres Strait Islander respondents said they also experienced health conditions other than HIV/AIDS which had a major impact for them which include asthma (2) and hepatitis C (3).

The issue of co-infection is of growing concern to PLWHA and HIV service providers. More than two thirds (16) of Aboriginal and Torres Strait Islander respondents have been tested for hepatitis C. One-third (8) of Aboriginal and Torres Strait Islander respondents have tested positive and are living with both HIV and hepatitis C. People infected with both viruses face greater difficulties in treatment choices and more uncertainty about how HIV and hepatitis C affect each other's development in the body. Almost one third of Aboriginal and Torres Strait Islander respondents have had hepatitis A (7) and almost half (11) have had hepatitis B.

Most Aboriginal and Torres Strait Islander respondents were actively monitoring their health through regular CD4/T-cell tests and viral load tests (which measure immune system damage and amount of virus in the body). The results of their most recent tests are shown in Table 1 below. Note that although 22 Aboriginal and Torres Strait Islander respondents said they had ever had a viral load test, only 14 gave responses for the result of their most recent test, which ranged from the month of the survey to nine months preceding the survey.

Table 1 Results of serological testing

Description	Result	Number
CD4/T-cell count	cells/ml blood	
little or no immune damage	over 500	13
moderate immune damage	250 - 500	5
severe immune damage	below 250	2
Viral load	copies/ml blood	
below detectable level	below 200 / 500	13
Low	500 - 10,000	0
Moderate	10,000 - 50,000	0
High	over 50,000	1

When asked who they usually see for HIV related treatment, Aboriginal and Torres Strait Islander respondents identified their HIV specialist (9) followed by their HIV GP (5) or HIV/AIDS organisations (5). For their main general medical treatment, Aboriginal and Torres Strait Islander respondents again identified their HIV specialist (11) followed by their HIV GP (6) or their generalist GP (4).

Of the four female Aboriginal and Torres Strait Islander respondents, three reported that they had had at least one pap smear in the last 12 months. Two of these women reported that their pap smear results were clear, one woman reported low grade intraepithelial abnormality (cervical intraepithelial neoplasia - CIN1) and another woman reported high grade intraepithelial abnormality (CIN3).

Mental health and support

Mental health is a growing concern in the HIV scene. Depression, anxiety, dementia and other related problems are important health issues.

The research found that in the last six months half (12) of the Aboriginal and Torres Strait Islander respondents had been taking medicine for anxiety, compared to 29.0% of the rest of the sample. In addition, three Aboriginal and Torres Strait Islander respondents reported taking anti-psychotic medication and one Aboriginal and Torres Strait Islander respondent reported taking medication for depression. Just over half of the Aboriginal and Torres Strait Islander respondents were using the counselling services available at HIV/AIDS organisations and other agencies.

Overall, most Aboriginal and Torres Strait Islander respondents have reasonable levels of support from their social networks, although four Aboriginal and Torres Strait Islander respondents didn't get 'a lot' of support from anyone. The richest sources of support came from partners/spouses (13), close friends (10), parents (7), HIV positive friends (8), and pets (10).

HIV treatments

Over the last few years, treatment options have developed to a point where many people living with HIV/AIDS have been able to imagine a future where HIV shifts from a life-threatening disease to an on-going illness that can be controlled. However, the reality of treatments is very complex. Drug side effects, the demands of treatment and future treatment options concern many people.

The majority of Aboriginal and Torres Strait Islander respondents (18) are currently using antiretroviral therapy (ARV) and this is very similar to the rest of the HIV Futures II sample. About half (11) are experiencing side effects including diarrhoea and nausea. Two thirds of those on medications (13) have problems managing the treatment, including remembering to take medication on time (7) and organising meals around medication (7). Despite these problems two thirds of Aboriginal and Torres Strait Islander respondents on medication (12) had not missed doses in the two days prior to completing the survey.

Six Aboriginal and Torres Strait Islander respondents were not currently using ARV and only one of these people said they had used ARV in the past. All but one of these people would consider using it in the future if needed.

Of those Aboriginal and Torres Strait Islander respondents who have ever used ARV, six have taken a break from treatments at some point in the past. This was usually to clean out their system or have a drug holiday or because the side effects became too severe.

Most Aboriginal and Torres Strait Islander respondents (18) are cautiously optimistic about ARV treatment and believe it offers people with HIV/AIDS a better future. Overall, the attitudes toward antiretroviral drugs expressed by Aboriginal and Torres Strait Islander respondents are consistent with the attitudes expressed by other PLWHA.

Some form of complementary/alternative therapy, particularly vitamin and mineral supplements, massage, meditation and acupuncture, is used by almost half of Aboriginal and Torres Strait Islander respondents (11). Most Aboriginal and Torres Strait Islander respondents (21) believe that these therapies can improve their well being, and half believe complementary/alternative therapy have a role in delaying the development of HIV illnesses (12) and reducing side effects of ARV (13). Overall, the attitudes toward complementary therapies expressed by Aboriginal and Torres Strait Islander respondents are similar to the attitudes expressed by other PLWHA.

Table 2 Use of antiretroviral drugs, prophylaxis for opportunistic infection (OI) and alternative therapies

	Aboriginal and Torres Strait Islander respondents	Non Aboriginal and Torres Strait Islander respondents
Using antiretroviral drugs	(18) 76.0%	73.4%
Using OI prophylaxis	(6) 26.9%	32.4%
Using alternative therapies	(11) 48.8%	55.1%

Sex and relationships

Dealing with sex and relationships while living with HIV is a major issue for people living with HIV/AIDS. More than half of the Aboriginal and Torres Strait Islander respondents said they were currently in a regular relationship (14). Table 3 shows that a high number of Aboriginal and Torres Strait Islander respondents were not having any sexual relationships at the time of the survey, although this was consistent with the rest of the survey population.

Almost two thirds of those Aboriginal and Torres Strait Islander respondents in a regular relationship have a spouse or partner also living with HIV/AIDS (8). All of these people have told their regular partner about their HIV, usually when they were diagnosed, or when they started the relationship. In most cases the response from their partner was supportive.

Table 3 Type of sexual relationship(s)

Sexual relationships	Aboriginal and Torres Strait Islander respondents % (n)	Non Aboriginal and Torres Strait Islander respondents %
Regular relationship only	31.7 (7)	25.8
No sex at present	30.1 (7)	25.1
Casual sex only	25.9 (6)	28.6
Regular relationship plus casual sex	8.7 (2)	18.2
Regular with two or more people	3.6 (1)	2.4

Due to the small numbers of Aboriginal and Torres Strait Islander respondents who are sexually active it is not possible to do any meaningful statistical analysis of their condom use or comparisons with other groups of PLWHA. Of the four Aboriginal and Torres Strait Islander respondents who reported their condom use with regular partners and who are in sero-discordant relationships (where their partner is HIV negative) condoms were sometimes or never used for vaginal and anal intercourse in the last six months. Of the three Aboriginal and Torres Strait Islander respondents who reported their condom use with regular partners and who are in sero-concordant relationships (where their

partner is HIV positive) condoms were never used by two respondents and always used by one respondent for vaginal and anal intercourse in the last six months.

Most Aboriginal and Torres Strait Islander respondents were afraid of infecting their current or future partners (19) and most agreed with the statement that *Few people would want a relationship with someone who has HIV* (17). Only six of respondents agreed with the statement *People with HIV now have a better chance to form partnerships and relationships*. Almost half (9) agreed with the statement *I am afraid of telling potential partners of my HIV status in case they reject me*. Despite this, only two Aboriginal and Torres Strait Islander respondents reported that HIV had a negative effect on their sexual pleasure

Only three Aboriginal and Torres Strait Islander respondents said they had dependent children. Respondents were also asked if they were considering having a child in the future. Table 4 shows that most Aboriginal and Torres Strait Islander respondents were not considering have a child in the future.

Table 4 Considering having a child

	<i>n</i>
No	21
I have decided to have a child/children in the future	0
I have thought about it but I haven't decided	1
I have thought about it but I have decided that it is too risky	1

Recreational drug use

People were asked about their use of non-prescription drugs, both those legally available and those currently banned in Australia.

Alcohol is the most commonly used recreational drug by Aboriginal and Torres Strait Islander respondents (17) and half the Aboriginal and Torres Strait Islander respondents (12) smoke cigarettes. This was consistent with the findings for non Aboriginal and Torres Strait Islander respondents. Three people reported using prescribed methodone.

The most commonly used illegal drug was marijuana used by around two thirds of Aboriginal and Torres Strait Islander respondents (15). Just over one quarter of Aboriginal and Torres Strait Islander respondents reported using other recreational drugs such as amyl (6), heroin (injected – 6), LSD (5), ecstasy (4), cocaine (not injected – 4; injected – 4), speed (not injected – 4; injected – 2). One person reported using steroids and one person reported using ketamine. It must be noted that we only asked respondents if they had used each of the drugs in the previous 12 months, not how often they used them. Use of many drugs in the gay scene is occasional rather than regular and this may inflate the rates reported here. The study also deliberately sampled among

injecting drug users and this may account for the higher rates of injecting drug use seen here.

More than half of the Aboriginal and Torres Strait Islander respondents said they had never injected illegal drugs and of those who had (10), two people had done so over a year ago. Of the eight Aboriginal and Torres Strait Islander respondents had injected drugs in the last 12 months, only one person had shared needles in the past 12 months. The last time this person shared a needle they employed risk reduction strategies including bleaching the needle and using the needle last.

Discrimination

Concerns about discrimination are an everyday issue for PLWHA. Almost half of the Aboriginal and Torres Strait Islander respondents (10) felt they had received less favourable treatment than other people at medical services because of their HIV and five have experienced less favourable treatment than other people at work as a result of having HIV/AIDS. Additionally, four Aboriginal and Torres Strait Islander respondents said they had changed their accommodation as a result of having HIV/AIDS in order to avoid harassment. The majority of Aboriginal and Torres Strait Islander respondents (19) reported that their HIV status was disclosed to another person when they didn't want it to be.

HIV community life and information

Most (20) of Aboriginal and Torres Strait Islander respondents had some contact with HIV/AIDS organisations. Aboriginal and Torres Strait Islander respondents said they used HIV/AIDS organisations mostly for treatment advice (15), social contact (11), peer support (11), counselling (9), pharmacy services (8), drug/alcohol treatment (6), library (5) and financial assistance and advice (5).

Most Aboriginal and Torres Strait Islander respondents spent a little time (8), some time (7) or a lot of time (6) with other PLWHA. More than three-quarters (18) of Aboriginal and Torres Strait Islander respondents have had someone close to them die of AIDS. Almost half (11 people) have been involved in the nursing and care of someone with AIDS in the last two years.

Table 5 below shows that for information about both treatments for HIV/AIDS and living with HIV/AIDS, the most commonly cited sources of information were the respondent's doctor who specialises in HIV treatment.

Table 5 Sources of information about HIV/AIDS for Aboriginal and Torres Strait Islander respondents

	Important for	
	treatments for HIV/AIDS	living with HIV/AIDS
Doctor who specialises in HIV	23	15
HIV/AIDS newspapers and magazines	15	12
Articles in gay press	11	12
HIV-positive friends	11	13
HIV/AIDS Organisation staff	10	11
Partner/lover	9	12
Pharmacist	8	0
Treatments Officer at HIV/AIDS organisation	8	7
Alternative therapist	7	9
Nurse	6	7
Positive women's organisation	4	3
Family	4	9
Other Doctor	3	3

Compared to other respondents, Aboriginal and Torres Strait Islander respondents nominated different people as important sources of information. For information about treatments for HIV/AIDS, Aboriginal and Torres Strait Islander respondents were more likely than other PLWHA to seek information from their pharmacists, their partners/lovers and their family, and less likely to seek information from the internet. For information about living with HIV/AIDS, Aboriginal and Torres Strait Islander respondents were more likely than other PLWHA to seek information from their alternative therapists, their partners/lovers, family and their Treatments Officer at an HIV/AIDS organisation.

When asked if a lack of information made it difficult to make decisions about a range of issue, the issue selected by the most Aboriginal and Torres Strait Islander respondents (12) was the management of side effects from ARV. Around one third of Aboriginal and Torres Strait Islander respondents also indicated difficulties with lack of information about financial planning (9), taking a break from antiretroviral therapy (8), interactions between ARV and other medications (8), and recreational drug use (8). Lack of information around using ARV drugs (6), changing ARV drugs (6) and legal issues (6) were also reported.

Employment

HIV infection has substantially disrupted many people's working lives and career development. Almost two thirds (14) of Aboriginal and Torres Strait Islander respondents had stopped work at some time in the past due to the impact of HIV on their emotional or physical health. Stress, depression and/or anxiety (12), low energy (10),

poor health (7), and expecting illness (5) were the most commonly listed reasons for stopping work.

Of those people who had left work in the past, only three have since returned to work. The reasons given by these three people for returning to work include: to do something worthwhile (3); financial reasons (2); for something to do (2); because of better physical health (2); or better psychological health (2); the possibility of flexible working hours (2) or the possibility of working part-time (2); and the social contact (2).

Around one quarter (6) of Aboriginal and Torres Strait Islander respondents are currently in paid employment, and of these people most (5) are working full time. Workers reported experiencing moderate to high stress levels with only one person reporting the level of stress in their work as low.

Half of the workers (3) had not disclosed their HIV status to anyone in their workforce and most (5) said they had experienced less favourable treatment than other people at work as a result of having HIV/AIDS.

Finances

One quarter (6) of Aboriginal and Torres Strait Islander respondents are living below the poverty line, which is consistent with the proportion of non Aboriginal and Torres Strait Islander respondents living below the poverty line (25.6%). More than one half of Aboriginal and Torres Strait Islander respondents (13) are primarily dependent on a government benefit or pension, eight people said their main source of income was a salary, and one person said their main source of income was superannuation/savings/annuity.

Respondents were asked to indicate whether or not in the six months prior to completing the survey they had experienced any difficulty meeting the costs of daily living. Responses from Aboriginal and Torres Strait Islander respondents indicated that:

- 17 had difficulty meeting the cost of going out (eating/drinking);
- 16 had difficulty meeting the cost of utilities (telephone/electricity/gas/water);
- 15 had difficulty meeting the cost of transport;
- 14 had difficulty meeting the cost of travel/holidays;
- 13 had difficulty meeting the cost of clothing;
- 13 had difficulty meeting the cost of entertainment;
- 12 had difficulty meeting the cost of food;
- 12 had difficulty meeting the cost of medical services (doctor, dentist etc.);
- 12 had difficulty meeting rent/mortgage/housing costs;
- 10 had difficulty meeting the cost of complementary therapies;
- 9 had difficulty meeting the cost of co-payments for medication for HIV/AIDS;

- 8 had difficulty meeting the cost of other prescribed medication;

As was the case with the rest of the sample of PLWHA, Aboriginal and Torres Strait Islander respondents reported difficulty meeting the costs of daily living and this was not necessarily a consequence of having an income below the poverty line.

DISCUSSION

It is difficult to interpret how representative the 23 Aboriginal and Torres Strait Islander respondents to this survey are of the wider Aboriginal and Torres Strait Islander HIV positive population. Historically there have been difficulties with and inconsistencies in the systematic enumeration of the Indigenous population in general in each State and Territory, as well as particular difficulties with recording Indigenous status in notification systems for communicable diseases and for causes of death (ABS, 1999). In addition to problems with health data collection systems, there are legitimate reasons why Aboriginal and Torres Strait Islander might not choose to self-identify their Indigenous status at the time of an HIV/AIDS diagnosis (Guthrie et al, 2000). Nonetheless, there are some indications that our sample broadly aligns with the population of Aboriginal and Torres Strait Islander PLWHA whose diagnoses have been notified and reported in the Guthrie et al paper in terms of gender, age at HIV diagnosis, mode of infection, and residence in non-metropolitan locations.

Notwithstanding issues of representativeness, the experiences of HIV positive Aboriginal and Torres Strait Islander respondents are similar in many important ways to other PLWHA. In terms of treatment uptake and experiences of treatment (including side effects, treatment breaks and attitudes to treatment), health status and monitoring, mental health and social support, sex and relationships, the experiences of Aboriginal and Torres Strait Islander respondents do not differ substantially from other HIV positive Australians. This shared experience of HIV positivity is important to remember when the mode of infection becomes the basis for divisive treatment of PLWHA in Australia.

Nonetheless, there are some differences for HIV positive Aboriginal and Torres Strait Islander respondents. As Guthrie et al (2000) note, Aboriginal and Torres Strait Islander PLWHA have generally been diagnosed with HIV at a younger age than other PLWHA, and this is true of respondents in the Futures II survey. Our Aboriginal and Torres Strait Islander respondents were also younger on average at the time of the survey than other PLWHA.

In relation to residence issues, Aboriginal and Torres Strait Islander respondents had less residential stability than other PLWHA in the survey. In terms of length of residence at their current address at the time of completing the survey, 22 respondents gave information. Nine of these people had lived at their current address for three years or less, 12 had lived at their current address for between three and six years, and only one had been at her current address for more than six years – she had been there for 13 years. The women were generally more residentially stable than the men, although this did not seem to be tied particularly to having dependant children, as the woman with the most dependant children was the one who had moved most recently. Of the 22 who gave information about their current postcode and the postcode they lived in when diagnosed, 17 had moved since diagnosis. Perhaps against expectations, much of this

movement was away from the metropolitan epicentres of the HIV epidemic in Australia. Of the 11 who had stayed within the same state, seven had moved from inner city postcodes to outer suburban postcode within the same city, three had moved from the inner city to regional centre and only one had moved from a regional centre to the inner city. Of the six who had moved interstate since diagnosis, two had moved from the inner city to regional centres, one had moved from the inner city to a small rural town, one had moved from a regional centre to the inner city, and two had moved from one inner city area to another inner city area. There were simply not enough people in the sample to discern patterns related to residential mobility, although further qualitative investigation might reveal whether issues like access to HIV services, changes in health status, or experience of unwanted disclosure of HIV status had contributed to decisions to move.

In relation to HIV treatments, six people were not on ARV, and we examined whether this was because of their gender, or because they lived in regions where access to HIV medications was more difficult. In our sample, the six people who were not on ARV were all men, and five of them lived in either inner or outer suburban areas of capital cities. Only one of the men not on ARV came from a regional centre. For the respondents to our survey at least, issues of access to HIV medication and specialist care were not the primary reasons given for not being on treatment, and unlike non-Indigenous PLWHA, women were not making noticeably different decisions to men about treatment uptake.

In relation to complementary/alternative therapies, nine of the 11 people using complementary/alternative therapies were accessing at least some of them from sources other than HIV/AIDS organisations. Although we did not ask specific questions about the use of bush medicines in the survey, these findings suggest that some Aboriginal and Torres Strait Islander respondents may be using bush medicines, and that more investigation of bush medicine use in HIV is warranted. The high rate of acceptability of complementary/alternative therapies among Aboriginal and Torres Strait Islander respondents suggests that many of them might access traditional therapies if these were available to them, particularly for delaying the development of HIV illnesses and reducing side effects of ARV.

There were two additional medical areas where the Aboriginal and Torres Strait Islander respondents differed noticeably from other PLWHA, although we are unsure how significant these differences are in broader population terms. Firstly, a third of this group was coinfecting with hepatitis C, and face greater difficulties in treatment choices and more uncertainty about how HIV and hepatitis C affect each other's development in the body. It is important that Aboriginal and Torres Strait Islander PLWHA and their health carers are aware of the impact of coinfection, and are aware of their hepatitis C status when making treatment decisions. We note that one third of the Aboriginal and Torres Strait Islander respondents to this survey had not been tested for hepatitis C, although this was a similar proportion to other PLWHA.

Secondly, a larger than expected proportion of Aboriginal and Torres Strait Islander respondents were taking medication for anxiety. There is growing evidence that depression, anxiety and other general psychological issues are critical factors in the well-being of HIV positive people. Given the range of other stresses in the lives of Indigenous Australians, it would not be a surprising finding that Aboriginal and Torres Strait Islander PLWHA led more anxious lives than non-Indigenous PLWHA. The survey also showed that four Aboriginal and Torres Strait Islander respondents didn't feel that they were getting "a lot" of support from anyone. Three of these respondents were men and one was a woman. Two of the men were from capital/inner city areas and the other man and the woman were from rural areas. Although it is clear that these people were getting some support, particularly from partners and friends, it seems likely from these results that there are specific issues relating to support for Indigenous PLWHA. The information from this survey suggests that this may be the case, but that more investigation is required particularly in the areas of culture-specific mental health issues and culturally appropriate delivery of mental health and social support services to Indigenous people living with HIV.

Taken together, the findings on sex and relationships from the survey suggest that for these Aboriginal and Torres Strait Islander respondents, HIV has made it harder for them to find partners and form relationships to a greater extent than for non-Indigenous PLWHA. Although for most HIV does not affect the pleasure that they get from sexual relationships, they worry about the possibility of infecting their partner.

Most recreational drug use, particularly alcohol use and smoking cigarettes, was similar to that of respondents who were not Aboriginal or Torres Strait Islander people. There were differences in the rates of injecting heroin and cocaine, but the small number of Aboriginal and Torres Strait Islander respondents who reported the use of injected heroin (6) and injected cocaine (4) meant that it is difficult to interpret what these rate differences may signify in real terms. One possible meaning is that our sample of Aboriginal and Torres Strait Islander PLWHA included an unrepresentative number of injecting drug users, which might explain the higher than expected prevalence of hepatitis C coinfection in this group.

Discrimination issues seem worse from Aboriginal and Torres Strait Islander people, particularly the issue of having one's HIV status disclosed without permission. We are not able to say from these data whether this is because of the interaction of various kinds of discrimination (for example, combinations of racism, homophobia and HIV related discrimination) in mainstream communities, or because of differences in the way privacy is dealt with in Indigenous communities. This is another area where more investigation is warranted.

It appears from our results that Aboriginal and Torres Strait Islander respondents choose different sources for information about HIV treatment and living with HIV than other PLWHA. Although these differences were statistically significant, the sample sizes were too small to judge whether they were meaningful in real terms. Of particular note, Indigenous PLWHA in our survey were less likely to seek information from the internet, although it is not clear from these results whether this is because of a lack of access to the internet, or for other reasons. The importance of partners and families as sources of information may mean that education strategies for Indigenous PLWHA need to be more inclusive in their targeting of these support people.

The results of the survey suggest that a different methodological approach would be beneficial for gaining information about Aboriginal and Torres Strait Islander people living with HIV/AIDS. Aboriginal and Torres Strait Islander people across Australia are culturally diverse, and many groups have first languages other than English. They live in a range of geographical, social and economic settings often with poor health status and in socially stressed environments. For this reason, it is important that further studies are designed in this area that are thoughtful, sensitive and embrace Indigenous research methodologies. Such studies would provide valuable information required to plan appropriate services for Aboriginal and Torres Strait Islander PLWHA.

REFERENCES

- ANCARD Working Party on Indigenous Australians' Sexual Health (1997) *The National Indigenous Australian's Sexual Health Strategy 1996-7 to 1998-9*. Canberra: Australian Government Publishing Service.
- Australian Bureau of Statistics (ABS) (1999) *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. ABS cat. No. 4704.0. Canberra: ABS.
- Australian Institute of Health and Welfare (1999) *National Drug Strategy Household Survey: First results*. AIHW cat. No. PHE15. Canberra: AIHW (Drug Statistics Series).
- Guthrie JA, Dore GJ, McDonald AM & Kaldor JM (2000) *HIV and AIDS in Aboriginal and Torres Strait Islander Australians: 1992-1998*. *Medical Journal of Australia*, 172: 266-269.
- Institute of Applied Economics and Social Research (1999) *Poverty lines: Australia, September quarter 1999*. Melbourne: Institute of Applied Economics and Social Research, University of Melbourne.
- National Centre in HIV Epidemiology and Clinical Research (NCHECR) (1999) *Australian HIV Surveillance Report 15(4)* Sydney: National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.
- National Centre in HIV Epidemiology and Clinical Research (NCHECR) (2001) *Annual Surveillance Report: HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia*. Sydney: National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.

