

# **ANWERNEKENHE III**

**Third National indigenous Gay, Sistergirl and Transgender  
HIV/AIDS and Sexual Health Conference**



**Strengthening Communities Through  
Prevention – Peer Education & Partnerships**

**Melbourne, Victoria  
May 15 – 17, 2002**

**Copyright Australian Federation of AIDS Organisations (AFAO)  
September 2002.**

This work may not be sold or used commercially. It may be reproduced in whole or in part with acknowledgement of the source.

Anwernekenhe III was sponsored by the Commonwealth Department of Health & Ageing through funding made available by the Office of Aboriginal & Torres Islander Health (OASTIH). AFAO would also like to acknowledge sponsorship through the AIDS Trust of Australia.

The Commonwealth Department of Health & Ageing does not necessarily endorse the recommendations made in this report.

Front cover design:  
'Us Mob' 2002  
Arone Meeks

AFAO can be contacted at:

PO Box 876  
Darlinghurst  
NSW 2010  
Phone: 02 9281 1999  
Fax: 02 9281 1044  
Internet: <http://www.afao.org.au>

## Forward

The Australian Federation of AIDS Organisations (AFAO) is proud to present this report of Anwernekenhe III the Third National Indigenous Gay, Sistergirl and Transgender HIV/AIDS Sexual Health Conference.

As the peak non-government organisation representing Australia's response to HIV, AFAO has committed itself in supporting Indigenous community responses to the threat HIV/AIDS poses. AFAO's work began in 1996 with the establishment of the Indigenous Gay, Sistergirl and Transgender Project at AFAO. This work has continued with the staging of Anwernekenhe II in 1998, the First National Sistergirl Forum in 1999 and implementation of the *AFAO National Indigenous Gay and Transgender Project Consultation Report and Sexual Health Strategy*.

The Report and Strategy along with conference recommendations from both Anwernekenhe and Sistergirl forums have shaped AFAO's ongoing response to the needs of Indigenous gay men, sistergirl and transgender communities. Outcomes over the past years have provided significant achievements along with the realisation that there is still much work to be done.

The past couple of years have seen shifts in the projects direction, incorporating recommendations from both the AFAO Strategic Directions Setting Process and the Druett Consulting Independent Review of the project. In an attempt to address this changing environment the former National Indigenous Gay and Transgender (Sistergirl) Steering Committee responded with a restructure to the committee membership and a new terms of reference.

This new restructure has since been endorsed by conference delegates at Anwernekenhe III and sets out a strategic approach to building on the past strengths and achievements of the project. The new AFAO National Indigenous Gay, Sistergirl and Transgender Strategic Alliance for HIV/AIDS and Sexual Health Promotion will become the key advisory body to the Indigenous project in meeting the future challenges and responses.

Several of those challenges were discussed at Anwernekenhe III and recommendations were proposed to progress work over the next few years. While most of the recommendations have been primarily targeted at AFAO, its member organisations, the National Aboriginal Community Controlled Health Organisations (NACCHO) and the Office of Aboriginal and Torres Strait Islander Health (OATSIH), we hope this report and its recommendations will be considered by all service organisations with a commitment to addressing the HIV/AIDS and sexual health needs of Indigenous communities.



Bill Whittaker  
National President  
AFAO

# CONTENTS

## Page

**Executive Summary**

**Conference Administrator Report**

**Indigenous Project Background**

**Acknowledgements**

**Recommendations**

**Anwernekenhe III Evaluation**

**Appendix**

### **1. Conference Programme**

### **2. Conference Papers**

- Anwernekenhe III summary of History - Colin Ross
- Position Paper: Review & Amendments to the Terms of Reference and Roles & Responsibilities of the Strategic Alliance - Michael Costello
- 'Here comes the 21st Century, it's gunna be much better for a girl like me' Developing Effective Aboriginal and Torres Strait Islander Sexual Health Partnerships and Networks - Chris Lawrence
- Work with us, not for us nor on our behalf - Mark Saunders
- Breaking the Silence - Gary Lee
- Dancing in the Dark (A look at injecting Drug Use and the Transmission of Blood Borne Viruses in Indigenous Communities - Elizabeth Harvey
- Developing Indigenous Branded Condoms - Rachel Tregonning
- Bloodborne viruses and injecting drug use among Indigenous Australians: Recent findings from epidemiological surveillance – Professor John Kaldor

- HIV Futures II - Aboriginal & Torres Strait Islander  
People Living with  
HIV - Dr Jon Willis

## Executive Summary

Anwernekenhe III, the Third National Indigenous Gay, Sistergirl and Transgender HIV/AIDS - Sexual Health Conference took place in Melbourne over three days from May 15 to 17, 2002. This was the third National gathering of Indigenous gay men, sistergirls and transgender communities, with previous Anwernekenhe forums been held in Hamilton Downs - Central Australia in 1994 and Mt Tamborine - South East Queensland in 1998.

It has been eight years since we first gathered at Hamilton Downs, where Indigenous gay and sistergirl HIV/AIDS issues were firmly placed on the agendas of service provision. Much has been achieved over this period through commitment, collaboration and hard work from key stakeholder HIV/AIDS organisations and the Indigenous gay and sistergirl community itself. Four years on from Anwernekenhe II and the release of the AFAO Indigenous Gay and Transgender Project Consultation Report and Sexual Health Strategy, it was time to take stock. Assessing where we have come from and looking at what has worked, what hasn't and where we need to focus our attention now.

The conference format was changed somewhat from previous Anwernekenhe forums, by extending invitations to Indigenous and non-Indigenous HIV/AIDS and sexual health organisations and service providers. This increase in participation ensured that conference objectives would be met under the theme of strengthening communities through prevention - peer education and allowing new partnerships to be formed. One hundred participants attended which included individuals from HIV/AIDS and sexual health stakeholder organisations.

The Anwernekenhe III conference programme commenced with an opening plenary (A Changing Environment). This session set out to provide all delegates with an overview of Anwernekenhe history, the work undertaken by the AFAO national project over the past four years since Anwernekenhe II and changes that needed to be considered to progress future work. The conference theme, "Strengthening Communities Through Prevention, Peer Education and Partnerships" provided a platform for all participants to discuss and deliberate current issues that would build on previous work, develop new relationships and progress into the future with renewed energy.

Day two of conference proceedings provided an Indigenous gay, sistergirl and transgender only stream, giving participants a confidential and supportive cultural space to discuss specific Indigenous gay, sistergirl and transgender community business. This was well received by all delegates and recommended for all future forums.

Two of the most significant issues discussed at Anwernekenhe III were that of injecting drug use and child sexual abuse. A paper, *Bloodborne viruses and injecting drug use among Indigenous Australians*: presented at Anwernekenhe III suggests an overall increase in injecting drug use in the

Australian Indigenous community. Anecdotal evidence discussed at this forum confirmed high incidence of injecting drug use.

The paper suggests that, "Prevalence of HIV infection monitored through needle and syringe programme surveys remains low for both Indigenous and non-Indigenous injecting drug users. Although numbers of HIV diagnoses attributed to injecting drug use in Australia remain small, there has been some increase in Indigenous diagnoses in more recent years".<sup>1</sup> Close monitoring of trends in both HIV and hepatitis C is recommended along with an assessment of access to harm-reduction strategies among Indigenous populations.

Child sexual abuse is a prominent and urgent issue for Indigenous communities and one that can be controversial. Indigenous communities have not always agreed to what the best way to respond to this issue should encompass and responses or lack of responses at times have been heavily criticised. With its devastating effects on community life and lives plus the associated HIV and sexual health risks the Indigenous gay and transgender community have often taken up the challenge to address this issue. Anwernekenhe III prioritised this issue within the conference programme to explore some of the challenges. Whilst it was agreed this was an issue that needed a whole of community approach, some of the outcomes provided realistic solutions to ensure that child sexual abuse does not become an ignored issue and is addressed in appropriate and functional ways.

Delegates called for urgent responses to both these critical issues in all areas from research, education and funding.

HIV treatments care and support was also highlighted as an issue requiring attention. Education around treatments for Indigenous communities is minimal and the needs of all communities from urban through to traditional need to be addressed. Access to treatments because of geographical isolation and confidentiality issues remain problematic and need serious consideration. The care and support issues of both, HIV positive individuals and their partners and/or families was stated as something still not been addressed in Indigenous communities. Delegates proposed that 'A Standard of Care Model' should be developed and that processes for HIV/AIDS organisations and Aboriginal Medical services continue to be developed to deliver more effective services to the positive community.

The conference theme demonstrated through its workshops and sessions that strengthening partnerships was fundamental in achieving future outcomes. Peer education was reiterated throughout the forum as the underlying principal in building capacity of communities to respond to sexual health issues. Delegates confirmed that sexual health was one of several health issues that communities are confronted with and community development principles are need to be considered by all who wish to work with Indigenous communities.

---

<sup>1</sup> National Centre in HIV Epidemiology and Clinical Research, Bloodborne viruses and injecting drug use among Indigenous Australians: Recent findings from epidemiological surveillance, June 2002, (unpublished)

The Anwernekenhe III conference has facilitated the sharing of knowledge and information as well as providing an opportunity to assess HIV/AIDS and sexual health responses to Indigenous gay, sistergirl and transgender communities. These forums are seen as a key opportunity for ongoing community consultation, empowerment and self-determination of health in general. Recommendations from Anwernekenhe III and along with the formation of the new Strategic Alliance, restructuring within the project at AFAO, and the future workplan all provide an enhanced capacity to respond to current and future challenges of addressing the HIV/AIDS and sexual health needs of Indigenous gay and sistergirl communities.

This Anwernekenhe III report provides a summary of conference proceedings with a snapshot of some of the current issues and most importantly recommendations to key stakeholders on where we need to be focusing our attention over the coming years. The predominant messages from this conference is that we still have much work to do in all communities, urban, rural and traditional ranging from education through to treatments. Some of these issues are quite complex and require partnerships and support structures to ensure the best outcomes are achieved. The conference unanimously passed 28 resolutions, presenting government and community organisations with many new challenges.

Michael Costello  
Senior Project Officer

### **Anwernekenhe III Conference Administrator Report**

A conference organiser/administrator was appointed by AFAO prior to Anwernekenhe III. This position was established to organise the conference venue, travel, accommodation and financial/administration aspects of Anwernekenhe.

Anwernekenhe III was sponsored by the Commonwealth Department of Health & Ageing through funding made available by the Office of Aboriginal & Torres Islander Health (OASTIH), funding was also provided through the AIDS Trust of Australia.

The hotel Ibis in Melbourne was selected as the conference venue as it provided all conference requirements and conference space was appropriate for a meeting of this size. The Hotel was also able to accommodate all participants. Hotel staff were all very supportive throughout the planning and running of the conference and all delegates were made to feel welcome. Delegate feedback of the accommodation and catering was very positive and had fulfilled the expectations and requirements of the conference planning committee.

Conference funding allowed AFAO to provide thirty scholarships to Indigenous gay men and sistergirls to attend. Scholarships applications were

provided equally across state and territories between urban, rural and remote communities. Applicants who were unemployed, students or HIV positive were given priority in this process. Scholarships included travel, accommodation and meals.

In conclusion, I would like to thank the organising and planning committee for their dedicated commitment in all the organisation of Anwernekenhe, the delegates to the conference for their wonderful support over the three days and finally the opportunity to participate in such a significant event.

Craig Tracey  
Anwernekenhe III Administrator

## Indigenous Project Background

In 1994, the Commonwealth sponsored the first national gathering of Indigenous gay men and sistergirls affected by HIV/AIDS, known as Anwernekenhe. The conference made a range of recommendations for improving the national response to the epidemic. Among these was a recommendation that the Commonwealth establish a project at AFAO to address the specific HIV/AIDS needs of Indigenous gay men, sistergirl and transgender communities. At Anwernekenhe, a working party was established from the delegates to oversee the establishment of this project as well as to pursue other conference recommendations.

Since the review of the Second National HIV/AIDS Strategy in 1995, there has been widespread recognition of the need to respond to the threat HIV poses to Indigenous communities. The third national HIV/AIDS strategy 1996/97-1998/99 and the fourth national strategy 1999/2000-2003/2004 identified Indigenous people as a priority group for any national response to the epidemic, and AFAO has endeavoured to participate in this emerging response.

The Indigenous project was established in 1996, under the auspices of the National Indigenous Gay and Transgender Working Party, now known as the Indigenous Gay, Sistergirl & Transgender Strategic Alliance for HIV/AIDS - Sexual Health Promotion. The project conducted a national consultation, which was published as part of the *AFAO Indigenous Gay and Transgender Project National Consultation Report and Sexual Health Strategy 1998 - 2000*. This was the first work ever to consider specifically the experiences and sexual health needs of Australian Indigenous gay men, sistergirl and transgender communities.

In 1998, AFAO (in collaboration with the Queensland AIDS Council) staged *Anwernekenhe II*, the Second National Indigenous Gay and Transgender Conference, held at Tambourine Mountain, Queensland, on the lands of the Kombumerri people. Delegates to Anwernekenhe II endorsed the Report and Strategy. The Report and Strategy have guided the project's activities, and the activities of AFAO's members. The strategy directs AFAO and its members to work collaboratively with Aboriginal community controlled health organisations.

The Indigenous Gay, Sistergirl and Transgender Project focus its work on the implementation of the *AFAO Report and Sexual Health Strategy*. This work includes capacity building to promote increased collaboration between AIDS Councils and Aboriginal Community Controlled Health Services.

To ensure this is done in a culturally appropriate and sensitive way, the Indigenous Gay, Sistergirl & Transgender Strategic Alliance for HIV/AIDS - Sexual Health Promotion provide support and guidance to both the project and AFAO management with up-to-date knowledge on specific Indigenous related issues that impact on HIV/AIDS, and sexual health for indigenous gay men and sistergirls.

AFAO has reported to the Office of Aboriginal and Torres Strait Islander Health (OATSIH) via the HIV/AIDS and Hepatitis C Section, Department of Health and Ageing, at six-monthly intervals. The project achievements have been set out in detail in these reports. In summary key areas of achievement include:

- National consultations with Indigenous gay men, sistergirls and primary health care providers.
- The National Indigenous Gay and Transgender Consultation Report and Sexual Health Strategy.
- Promotion of the Report and Strategy with member organisations, and endorsement of the Strategy by AFAO membership.
- Anwernekenhe II, staged in Queensland with delegates endorsing the strategy
- Signing of the Memorandum of Understanding between NACCHO AFAO and NAPWA.
- Establishment of the Indigenous Projects Officer Network (IPON)
- First National Indigenous Sistergirl Forum Staged on Magnetic Island in September 1999 and comprehensively reported on in the *First National Indigenous Sistergirl Forum Report*.
- Development of key resources including the 1999 “Indigenous Pride” calendar; “We’re Family Too” poster; “Access For All” training package; and “Anwernekenhe News”
- Cultural Awareness and Sensitivity Package plus the Indigenous Treatments resource (currently in final draft stage).

AFAO’s Indigenous Project, and the activities of our member organisations, has worked to build capacity, raise awareness, provide peer support and promote behaviour change with Indigenous gay men, sistergirl and transgender communities. Our work with Indigenous gay men and sistergirls has been, and remains, groundbreaking.

When the idea of a project at AFAO emerged from Anwernekenhe I, there were no Indigenous AIDS Council based projects in Australia. There are currently three projects employing ten workers. This means that there is a significantly enhanced capacity within AFAO’s membership to undertake implementation of the strategy.

In 1999 and into 2000 there was a growing sense within the AFAO membership, and across some stakeholders, that some reconsideration of ways to maximise Indigenous input and advice to the project may be warranted. Discussions between AFAO management and the former NIG&TSSC highlighted the need for alternatives to be developed that allowed the project to develop new ways of responding to emerging issues as well as working with it’s current priorities. The need to develop clearer models for AFAO - a non-Indigenous organisation - to be advised by Indigenous communities was also highlighted.

At the 1999 November AFAO AGM, there was discussion among member organisations about how the project could best reach its outcomes, and how independent Indigenous input could best be facilitated and utilised. A resolution was passed to review the project. A review was envisaged to assess the effectiveness of the Indigenous Gay, Sistergirl and Transgender Project to date, including the way it receives its indigenous advice, and to assist in refining the project and improving future outcomes for Indigenous gay men and sistergirls.

AFAO established a review reference group. This reference group contracted an independent review team to undertake a review of the AFAO Indigenous Project. The reviewers were provided with the following terms of reference:

1. How the project has performed to date and what have been its greatest strengths
2. Should the project brief be expanded to include other groups?
3. How Indigenous input into the project is best facilitated
4. What types of policies or procedures are required to enhance collaboration between AFAO and the relevant source of expert advice on Indigenous health?
5. What should be the focus of the AFAO Indigenous project's work?

The reference group met three times during the development of the review and feedback was provided on the report's content. During this time it became apparent that there were some differences of understanding between the reference group and the review team as to what the review was attempting to achieve. The review team did not wish to incorporate all the perspectives of the reference group and this resulted in the AFAO Board of Directors requesting that a response to the review should be prepared. The response is now known as the *A Changing Environment* document that incorporates a *How to Action Plan*.

The review of AFAO's Indigenous project has now been successfully completed. In order to progress the project's work, AFAO now needs to plan for future activities. The first stage is to progress the elements of this How to Action Plan, and to work with all key stakeholders to progress all of the recommendations found throughout this response to the review.

"Ownership in partnership" was overwhelmingly supported as a model that would progress the implementation of the Indigenous project. In real terms this means joint collaboration with an emphasis on increased Indigenous input into decision making processes with project staff taking a more senior role within AFAO.

When the idea of an Indigenous review was considered, the AFAO membership was prompted to examine the possibility of the Indigenous Gay, Sistergirl and Transgender Project expanding its brief not only in response to epidemiological and other data, but also to reflect accurately at a national level the work being undertaken by some AIDS Councils. This meant that the review was asked to consider, not only the effectiveness of the Indigenous

Project but also, whether the Project brief should be expanded to include other "at risk" groups.

While epidemiological and social research supports a focus on gay men and other men who have sex with men, some AIDS Councils were reconsidering their overall work, including Indigenous projects. Consideration has been given to the possibilities of working with Indigenous people who do not identify as gay or sistergirl, due to factors such as:

- Higher incidence of HIV infection among Indigenous women than among non-Indigenous women
- That sexuality is a less defining characteristic for Indigenous men who have sex with men than for their non-Indigenous counterparts
- Anecdotal evidence of increasing injecting drug use within Indigenous communities
- Reported high incidence of Indigenous Australians engaged in sex work, including opportunistic sex work

Whilst examining these possibilities the concept of a "whole of community" approach was raised as a culturally appropriate way of working with Indigenous communities. This concept builds on the strengths of the project and the Indigenous Gay, Sistergirl & Transgender Strategic Alliance for HIV/AIDS - Sexual Health Promotion. The "whole of community" approach allows for collaborative ventures with other Indigenous groups to be explored, whilst not shifting focus of the project. It has been affirmed that the work of the project will remain clearly focused on the needs of Indigenous gay men sistergirl and transgender communities.

The review of the project acknowledges a broad range of project achievements. However it also proposes some useful modifications to current practice and poses some challenges for next few years. Recommendations arising from the review form the core of AFAO's response document and are also reflected in the future work plan of the Indigenous Gay, Sistergirl & Transgender Project.

The workplan foresees initiatives, which include consideration of the issue of sexual identity for Indigenous youth. Sexual abuse and injecting drug use. The development of links between AIDS Councils and AMS's will continue, through the Access for All package and other means. Collaborative work with NACCHO will hopefully be enhanced, through the inclusion of a NACCHO representative to the strategic Alliance.

Evaluation will be expanded, and this has been reflected in the proposed workplan and budget. Resources will be evaluated, as will implementation of the Access For All, and the Cultural Awareness packages and the activities of IPON. The AFAO Indigenous Gay & Transgender Sexual Health Strategy will be reviewed. Performance of key agencies will be assessed against the strategy and decisions made about next steps, whether a new strategy is required or whether efforts to implement the current strategy need to be enhanced.

## Acknowledgements

Anwernekenhe III, the Third National Indigenous Gay, Sistergirl and Transgender HIV/AIDS Sexual Health Conference involved eighteen months of work from initial funding proposals through to programme development and implementation. Majority of this work was developed and overseen by the AFAO National Indigenous Gay, Sistergirl and Transgender Steering Committee.

The **Steering Committee** included:

Robert Smith	Convenor (WA)
Peter Pinnington	Deputy Convenor (ACT)
Shane Burgess	South Australia
Michael Murray	Victoria
Vincent Strong	Queensland
Denis Ridgeway	New South Wales
Jacki Timpngwuti	Northern Territory
Crystal Johnson	Sistergirl Representative
Mark Saunders	Research Representative
Diana Readshaw	Commonwealth Dept of Health and Ageing (CDH&A)
Dermot Ryan	Australian Federation of AIDS Organisations (AFAO)
Michael Costello	Australian Federation of AIDS Organisations (AFAO)

The final stages of development and implementation of Anwernekenhe III were overseen by the Anwernekenhe III Planning and Organising Committee.

The **Anwernekenhe III Planning and Organising Committee** included:

Robert Smith	NIGS&TSC
Michael Murray	NIGS&TSC
Crystal Johnson	NIGS&TSC
Hugh Tippo	AFAO Indigenous Projects
Officer Network (IPON)	
Maurice Shipp	Department of Human Services (South Australia)
Neville Fazulla	Life Choices (Alice Springs)
Tony Creighton	National Association of People Living with HIV/AIDS (NAPWA)
Diana Readshaw	Commonwealth Dept of Health and Ageing (CDH&A)
Richard Scanlon	Office of Aboriginal & Torres Strait Islander Health (OATSIH)
Bridgette Carrick	National Aboriginal Community Controlled Health Organisations (NACCHO)
Corey Czok	Australian Federation of AIDS Organisations (AFAO)
Michael Costello	Australian Federation of AIDS Organisations (AFAO)
Craig Tracey	Australian Federation of AIDS Organisations (AFAO)

AFAO would also like to acknowledge the many other individuals over the past four years who were members of the National Indigenous Gay, Sistergirl

and Transgender Steering Committee.

These members include:

Rusty Nannup (Sistergirl)	James Mullet (VIC)
Darren Darcy (NSW)	Tony Creighton (PLWHA)
Mark Saunders (QLD)	Gregory Phillips (QLD)
Alan Radford (TAS)	Maurice Shipp (NSW)
Phillip McGuinness (NT)	Michael Costello (QLD)
Thomas Barry (QLD)	Gilbert Gorgeous Uta (TSI)
Stanley DeSatge (NT)	

AFAO would also like to acknowledge the Anwernekenhe III guest speakers and session chairs.

These included:

#### **Session chairs**

Colin Ross

Neville Fazulla

Gary Lee

Kooncha Brown

Mark Saunders

Maurice Shipp

Ross Duffin

#### **Guest speakers**

Professor John Kaldor

Jon Willis

Ron Johnson

Don Baxter

John Day

Jenny McDonald

Chris Lawrence

Colin Ross

Dr

A very special thankyou must be given to Tim Leach who was Deputy Director Of AFAO and managed the Indigenous Project from its inception at AFAO until his resignation in 2001.

Anwernekenhe III was supported by the Commonwealth Department of Health and Ageing through funding made available by the Office of Aboriginal & Torres Strait Islander Health (OATSIH). AFAO would also like to acknowledge sponsorship through the AIDS Trust of Australia.

In July 2002, the new **AFAO Indigenous Gay, Sistergirl & Transgender Strategic Alliance for HIV/AIDS - sexual Health Promotion** was formed and consists of the following members:

**Indigenous gay, sistergirl  
& transgender community  
representatives**  
**Organisational representatives**

Mark Saunders	Australian Federation of AIDS Organisations (AFAO)
Gary Lee	Indigenous Projects Officer Network - AIDS Councils (IPON)
Colin Ross	National Association of People Living with HIV/AIDS (NAPWA)
Corey Czok	National Aboriginal Community Controlled Health Organisations (NACCHO)
Crystal Johnson	Australian Society of HIV Medicine (ASHM)
Clyde DuBois	Commonwealth Dept of Health & Ageing

## **ANWERNEKENHE III RECOMMENDATIONS**

The *AFAO National Indigenous Gay and Transgender Consultation Report and Sexual Health Strategy 1998 - 2000*, was endorsed by conference delegates as a 'living' document and the strategy recommendations implementation should be continued.

The following recommendations were put forward to AFAO at Anwernekenhe III. AFAO's response to these recommendations will be guided through collaboration with the National Indigenous Gay, Sistergirl and Transgender Strategic Alliance for HIV/AIDS & Sexual Health Promotion.

### **A Developing Partnerships & Networks**

1. That Queensland AIDS Council pursue the development of partnerships with the Torres Strait Islander Health authority to address and progress cross border issues.
2. AFAO investigate the possibilities of establishing partnerships with disability services to address the mental and physical health needs of Indigenous gay men and sistergirls.
3. That State and Territory AIDS Councils and Aboriginal Medical Services develop local Memorandum of Understandings to progress collaboration and improve service provision to Indigenous gay men and sistergirl communities.
4. That the AFAO Indigenous Strategic Alliance develop and adopt a communication strategy with a focus on information sharing amongst State and Territory AIDS organisations, PLWHA organisations, Aboriginal Medical Services other peak HIV/AIDS stakeholder organisations.
5. That a position be maintained on the AFAO Strategic Alliance for a representative of the IPON Network.
6. That OATSIH fund the establishment of Indigenous gay men and sistergirl social support networks in remote and rural communities to develop network groups to identify and prioritise local issues.
7. That NACCHO promote cultural appropriateness to ensure that non-Indigenous providers of health services to Indigenous Australians provide diagnoses, tests and treatments which are culturally appropriate and which address the needs of Indigenous gay men and sistergirls.

**B  
Development**

**Peer Education-Prevention & Community**

8. That AFAO investigate the possibilities around an 1800 line for use by Indigenous gay men and sistergirls to facilitate HIV/AIDS - sexual health support and information exchange.
9. That the AFAO Indigenous Strategic Alliance advocate for a national career structure for Indigenous workers within AIDS Councils.
10. That the AFAO Indigenous Strategic Alliance continues to advocate for Indigenous Projects in State and Territory AIDS Councils.
11. That peer education initiatives consider the concept of reconciliation when developing programmes and campaigns that target Indigenous gay men and sistergirl communities.
12. That Indigenous HIV/AIDS - sexual health stakeholder organisations acknowledge Indigenous time frame and processes when developing partnerships.
13. That the AFAO Indigenous Project develops a fact sheet of acronyms and national HIV/AIDS - sexual health organisational structures.
14. That NACCHO promote cross cultural awareness training for Health professional working in Indigenous communities.
15. That AFAO conduct a literature review to access the current Injecting Drug Use health promotion material available.
16. That OATSIH fund programmes which target initiatives addressing Injecting Drug Use amongst Indigenous communities.

**C**

**HIV/AIDS & Sexual Health Forums**

17. That Anwernekenhe conferences are conducted every two years rather than four, to promote continuity and sustainability of initiatives.
18. That Indigenous gay men, sistergirl and transgender only cultural space be included in all future Anwernekenhe forums.
19. That State and Territory Indigenous gay and sistergirl HIV/AIDS - sexual health forums should be conducted to facilitate specific community issues.

**D**

**People Living with HIV/AIDS**

20. That AFAO and NACCHO work collaboratively with the Australian Society for HIV Medicine (ASHM) in developing "A Standard of Care" model for Indigenous Australians.

21. That HIV/AIDS organisations and Aboriginal Medical Services develop processes for both stakeholders to effectively deliver HIV/AIDS treatments information that is culturally specific.
22. That the AFAO Indigenous Strategic Alliance develops a sub-committee to progress the above recommendations.

**E Sexual Abuse - Health Support**

23. That AFAO consider a national Indigenous gay, sistergirl and transgender sexual abuse strategy.
24. That National Indigenous peak health organisations and projects convene a national conference to access and progress the issue of child sexual abuse.
25. That the AFAO National Indigenous Gay, Sistergirl and Transgender Strategic Alliance for HIV/AIDS and Sexual Health Promotion, prioritise the issue of child sexual abuse in its work plan.

**F Other Recommendations**

26. That there be a continuation of the Indigenous and Ethnic Minority Communities Track at the 7th International Congress on AIDS in Asia and the Pacific in Kobe, Japan in 2003.
27. That ICAAP support the indigenous people of the region in their struggle for recognition (including by and within developed nations of the region) as populations at risk of HIV/AIDS infection who generally experience health conditions similar to the developing world regardless of geographic location.
28. That The 7TH ICAAP congress supports the staging of a satellite Indigenous and Ethnic Minority Communities Forum that substantially links with other community forums at the 7th ICAAP.

*Indigenous participants made recommendations 26/27/28 at the 6th ICAAP. These recommendations were put forward again, recommending that AFAO advocate to the 7th ICAAP Congress for their consideration.*

# **ANWERNEKENHE III**

**3<sup>rd</sup> National Indigenous Gay, Sistergirl & Transgender HIV/AIDS & Sexual Health  
Conference 15-17 May 2002**

## **FINAL EVALUATION**

**Tim Leach and Maurice Shipp  
July 2002**

# **Anwernekenhe III Evaluation**

## **1. Introduction**

Anwernekenhe III, the third national Indigenous gay men and transgender/sistergirl HIV/AIDS & sexual health conference, was held in Melbourne in May 2002 over a 3-day period. The conference's program reflected the main theme of "strengthening communities through prevention, peer education and partnerships".

Anwernekenhe III was supported by the Commonwealth Department of Health and Aging through funding made available by the Office of Aboriginal and Torres Strait Islander Health (OATSIH), and also received sponsorship from the AIDS Trust of Australia.

The conference was attended by approximately 100 delegates.

This evaluation summary is presented in reflection of the aims and rationale of the Anwernekenhe III Conference.

**As with Anwernekenhe I and II, it is not possible to fully reflect the value of the conference through the recording of responses on a questionnaire. An understanding of the conference's value must involve recognition that much of the event's productivity and successes resulted from the culmination of an array of personal interactions, stories shared, experiences gained, and through a sense of "being there".**

As a consequence, much of the event's "Indigenous culture" is not recorded or evaluated in detail within this summary. It is encountered through understanding the experiences, learning processes and interactions which were fostered by the event - for individuals and groups. The following evaluation summary needs to be understood in this context.

## 2.

### **The Evaluation Process**

There were separate processes of evaluation to obtain feedback from all areas of the conference, from the initial consultation to the final evaluation. This summary focuses on feedback provided by delegates in their responses to set questions. The questions were set by the evaluators in consultation with the Indigenous Gay and Sistergirl Project of the Australian Federation of AIDS Organisations (AFAO). The evaluation form is attached to this summary at Appendix 1

Participants were given evaluation forms at the commencement of the third and final day of conference proceedings. The evaluation forms were designed to obtain the maximum amount of information relating to the conference while being easy to complete, keeping responses focussed and preserving the anonymity of respondents.

Questions were developed to examine various components of the conference and to allow participants ample opportunity to identify individual positive and negative views of the event. Areas that were evaluated included:

- The presenters and guest speakers,
- The workshops and sessions, and
- The conference facilities.

A total of 32 responses were received. This represents a return rate of approximately 32%.

### 3. Summary of Responses to Evaluation Questions

#### 3.1 Relevance, clarity and cultural appropriateness of sessions

Following is a summary of findings based on individual feedback obtained from completed evaluation forms. Results are represented in table format and in narrative style.

##### 3.1.1 Partnerships and networks

Delegates were asked to reflect on the “Developing partnerships and networks” session. Delegates were presented with three statements:

- I found the session relevant and useful.
- The session was presented in a clear and useful way.
- The session was culturally OK.

Delegates were then asked to respond to these statements indicating whether they strongly disagreed with the statement, disagreed with the statement, were not sure, agreed with the statement or strongly agreed with the statement.

Partnerships	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Relevant 32		1	2	19	10
Clear 30		1	4	15	10
Culturally OK 27			6	10	11

The session on developing partnerships and networks was generally considered relevant and useful. Of the 32 delegates who responded to this question, ten strongly agreed that it was relevant and useful while another nineteen agreed with the proposition. Two delegates were not sure and one disagreed. Overall, 91% of respondents gave the session’s relevance a positive rating.

Thirty delegates commented on whether the session was clearly and helpfully presented. Ten said they strongly agreed that this was the case, fifteen agreed and four were not sure. One disagreed. Overall, 83% of respondents gave a favourable response.

Eleven respondents out of 27 strongly believed the session to be culturally relevant. Another ten respondents agreed that the session was appropriate, with six people responding that they were not sure. In total 78% of respondents offered a positive response to this question.

Five respondents listed this session as their favourite. No-one listed this session as her or his least favourite.

##### 3.1.2 Treatments stream

Delegates were asked to reflect on the “Treatments, care and support” sessions (including the Day 1 plenary and the treatments workshop). Delegates were presented with three statements:

- I found the sessions relevant and useful.
- The sessions were presented in a clear and useful way.
- The sessions were culturally OK.

Delegates were then asked to respond to these statements indicating whether they strongly disagreed with the statement, disagreed with the statement, were not sure, agreed with the statement or strongly agreed with the statement.

Treatments	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Relevant 29			3	16	10
Clear 28			1	20	7
Culturally OK 27			5	16	6

Of the 29 respondents who rated the session for relevance, 90% gave a positive response (ten strongly agreed that the session was relevant and useful with sixteen agreeing). Three respondents indicated they were unsure of the relevance.

Twenty-eight delegates rated the session for clarity of presentation, with seven strongly agreeing that the session was clearly and usefully presented, twenty agreeing with this proposition and one saying they not sure. The positive rating was 96%.

Eighty-one percent of respondents agreed that the session was culturally OK (6 strongly agreed and 16 agreed). Five respondents said they were not sure.

One delegate nominated the treatments stream as the conference’s best feature. One nominated it as the worst.

### 3.1.3 Peer education/prevention and community care

Delegates were asked to reflect on the “Peer education/prevention and community care” session. Delegates were presented with three statements:

- I found the session relevant and useful.
- The session was presented in a clear and useful way.
- The session was culturally OK.

Delegates were then asked to respond to these statements indicating whether they strongly disagreed with the statement, disagreed with the statement, were not sure, agreed with the statement or strongly agreed with the statement.

Peer Education	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Relevant 29			3	14	13
Clear 28		1	1	16	10
Culturally OK 27			2	16	9

Ninety-three percent of respondents either strongly agreed (13 delegates) or agreed (14 delegates) that the session was relevant. Three delegates were not sure.

Ninety-three percent of the 28 respondents to the question on clarity said the sessions was clear and helpfully presented (10 strongly agreed and 16 agreed) with one delegate being not sure and another disagreeing.

Nine out of 27 respondents strongly believed the content to be culturally OK, with sixteen agreeing and another two being not sure. The overall positive rating for cultural appropriateness was 93%.

This session was the most popular at the conference, with seven delegates nominating it as their favourite session. One delegate nominated the session as the conference’s worst.

### 3.1.4 New and innovative projects

Delegates were asked to reflect on the “New and innovative projects” session. Delegates were presented with three statements:

- I found the session relevant and useful.
- The session was presented in a clear and useful way.
- The sessions was culturally OK.

Delegates were then asked to respond to these statements indicating whether they strongly disagreed with the statement, disagreed with the statement, were not sure, agreed with the statement or strongly agreed with the statement.

<b>Innovative Projects</b>	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Relevant 29		1	1	18	9
Clear 26		2		14	10
Culturally OK 25		1	3	13	8

When asked whether the session was relevant and useful, nine respondents agreed strongly that this was the case, eighteen agreed, one was not sure and one disagreed. This represents an overall positive rating of 93%.

Of 26 respondents, ten strongly agreed that the session had been clearly and helpfully presented, fourteen agreed and 2 disagreed. This represents a positive rating of 92%.

Only one out of 25 respondents thought the sessions culturally inappropriate, three were not sure while 84% either strongly agreed (8) or agreed (13) that the session was culturally OK.

This was the favourite session of three respondents. No delegates recorded this as their least favourite session.

### 3.1.5 Review of the National Indigenous Strategy

Delegates were asked to reflect on the “Review of the National Indigenous Consultation Report & Sexual Health Strategy” session. Delegates were presented with three statements:

- I found the session relevant and useful.
- The session was presented in a clear and useful way.
- The session was culturally OK.

Delegates were then asked to respond to these statements indicating whether they strongly disagreed with the statement, disagreed with the statement, were not sure, agreed with the statement or strongly agreed with the statement.

<b>Report on the Review</b>	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Relevant 19			7	6	6
Clear 19			6	7	6
Culturally OK 19			6	6	7

Six respondents strongly agreed that the session was relevant, six agreed that this was the case and seven were not sure. This represents an overall positive rating of 63%.

Six respondents strongly believed the session was clear. Seven respondents agreed with this proposition and six were unsure. This represents an overall positive rating of 68%.

Seven delegates strongly agreed that the session was culturally OK, six agreed and six were unsure. This represents an overall positive rating of 68%.

No-one listed this session as their favourite session although for one delegate it was the least favourite.

### 3.1.6 Resources

Delegates were asked to reflect on the “Resources” sessions (including the History, Health and Harmony session, the sistergirl resource session and the treatments resource focus testing). Delegates were presented with three statements:

- I found the sessions relevant and useful.
- The sessions were presented in a clear and useful way.
- The sessions were culturally OK.

Delegates were then asked to respond to these statements indicating whether they strongly disagreed with the statement, disagreed with the statement, were not sure, agreed with the statement or strongly agreed with the statement.

Resources	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
Relevant 24			3	9	12
Clear 23			5	9	9
Culturally OK 23			3	10	10

Twelve respondents strongly agreed that these sessions were relevant, nine agreed that this was the case and three were not sure (overall, 87% of respondents gave the session a positive rating for relevance).

Nine respondents strongly agreed that the sessions had been clearly and usefully presented, nine agreed that this was so and five were unsure (a positive rating of 78%).

Ten respondents strongly agreed that the sessions were culturally OK, another ten agreed and three were unsure (a positive rating of 87%).

For a number of delegates, these sessions represented the conference highlight. Three delegates nominated the sistergirl resource discussion as the conference’s best feature. Two delegates regarded the History, Health and Harmony session as the best, with another two describing it as their least favourite.

### 3.2 **Favourite sessions**

Participants were asked to identify their favourite workshop and session. The responses were as follows in order from most common response to least common response. The number of times the response was recorded is in brackets.

1. Peer education (7)
2. Developing partnerships (5)
3. Indigenous only (3)
4. Sistergirl resource (3)
5. Innovative projects (2)
6. History health harmony (2)
7. Research (1)
8. Sexual abuse (1)
9. Treatments (1)
10. Opening plenary (1)

### 3.3 Least favourite workshop

Participants were asked to identify their least favourite workshop and session.

The responses were as follows in order from most common response to least common response. The number of times the response was recorded is in brackets.

1. Opening plenary (3)
2. History Health & Harmony (2)
3. Peer education (1)
4. Alliance discussion (1)
5. Treatments (1)
6. Recent research (1)
7. Treatment care & support (1)
8. The first day (1)
9. Strategy review (1)

### 3.4 Is the Conference duration appropriate?

The delegates were asked whether a three-day program was appropriate and asked to tick one of three alternative responses. The responses are set out below.

Too short?	8
About right?	25
Too long?	0

Twenty-five respondents suggested that the three-day conference was about the right length. Eight respondents believed the conference was too short. No respondents suggested the conference was too long.

### 3.5 Was the decision to restrict attendance for one day to Indigenous gay men and sisters appropriate?

Delegates were asked whether the decision to restrict one day's proceedings to Indigenous gay men and sisters was appropriate. Delegates were asked to tick one of three alternative responses.

Good idea?	25
Not sure?	4
Bad idea?	2

While two respondents suggested that having one day restricted to Indigenous gay and sister delegates only was a bad idea, the overwhelming majority of respondents to this question (81%) considered it a good idea. Four were unsure.

### 3.6 Were the conference facilities appropriate?

Delegates were asked whether the conference facilities (including accommodation, venue and food) were appropriate and asked to tick one of three alternative responses.

Not satisfactory?	0
Satisfactory?	14
Good?	19

There was a general acknowledgment amongst delegates who had attended previous conferences that Anwernekenhe had come a long way from the basic facilities of Hamilton Downs 1994. No respondents to the survey were dissatisfied with the facilities. Fourteen delegates rated the facilities as satisfactory with nineteen giving them a good rating.

### 3.7 **Would you like to see another Anwernekenhe Conference?**

Delegates were asked whether there should be an Anwernekenhe IV event and asked to tick one of three alternative responses.

Yes?	29
Not sure?	2
No?	2

Of 33 delegates, 29 believed there should be another conference, with two suggesting no and two suggesting they were not sure.

### 3.8 **Would you attend another Anwernekenhe Conference?**

Yes?	30
Not sure?	1
No?	2

Thirty out of 33 respondents said they would like to attend another Anwernekenhe event, with two saying they would not and a final delegate suggesting they were not sure.

### 3.9 **What should be changed?**

Finally, delegates were asked to comment on what they would change about future events or what they would like to see at Anwernekenhe IV that they did not obtain from Anwernekenhe III. Delegates were not prompted with alternatives so the responses were varied. The comments are set out below:

- Fewer difficult personalities
- Less infighting
- More cohesiveness
- Opening plenary needs to be inspirational rather than political
- Need for better processes to resolve disputes
- Explanation of acronyms
- Better explanation of research terms
- Map of health bureaucracy
- More time for yarn
- More time for workshops
- More workshops
- More Indigenous delegates
- More lesbian/female involvement
- More presentations from Indigenous people
- More HIV scientific/research information
- Workshop for whites working against racism
- Forum for practitioners to talk about their experiences - good and bad
- Easier scholarships program
- More emphasis on strategic direction
- More obtaining information from delegates - get information from the grass roots

- Focus testing
- Developing resources
- Sharing ideas
- More representatives from AIDS Council, including office bearers
- Forum for reviewing AIDS Council performance
- Need to know people before arriving - support beforehand
- Social gathering beforehand
- A buddy system
- Let AIDS Councils know beforehand who is coming so a social gathering can be arranged or delegates can be better supported
- More communal eating
- Money for warm clothes
- Who were the Torres Strait Islanders?
- Don't split Indigenous from non-Indigenous
- Put the restricted day at the end
- More formal networking of Indigenous projects from around Australia
- More opportunities to develop partnerships, especially with research

## 4. Overall patterns in feedback

Looking for patterns in the feedback it is possible to identify the following themes:

### 4.1 Politics

The political component was a prominent feature of the conference. A number of delegates referred to this aspect of the conference in their responses. Politics were particularly a focus of discussions given the proposed changes to the AFAO Indigenous Gay and Sistergirl Project's governance structure. These changes were appropriately central to discussions, and differences of opinion were unavoidable. A number of delegates expressed strong views around the future management of the project, its future governance structure and the direction of the project, and these views reflected a strong investment in the project and a desire to ensure its future success.

It is probable, however, that there will be prominent political dimensions to future conferences and that vigorous discussions and debates will be an ongoing feature of Anwernekenhe events.

While a number of delegates may have felt uncomfortable with some of the intensity of debate, most responses which referred to the political differences were more about conflict management than conflict avoidance. Most responses which addressed the issue of conflict acknowledged either directly or by implication the need for debate.

Five respondents were critical of the political infighting. Of the five, however, three offered suggestions more in line with conflict management than avoidance. One delegate suggested that the next conference include better mechanisms for promoting cohesiveness and a second suggested that there be improved processes for dispute resolution. Another delegate suggested that the opening plenary needs to be inspirational rather than political: this is consistent with the approach taken by many conferences where there is an attempt to inspire and expand thinking through the opening plenary instead of going directly to the issue most likely to polarise delegates.

One delegate suggested that attempts be made to manage bad language as some delegates found this offensive.

### 4.2 Issues for new delegates

There were some suggestions that for new delegates in particular, the conference may have seemed a bit overwhelming. In this context, the early focus on discussions of governance and politics may have been even more intimidating with one delegates suggesting that some other delegates did not return to later sessions because of the conflict.

A number of delegates suggested that there be steps taken to familiarise delegates with systems or with other delegates prior to or at the commencement of the conference. One delegate suggested that delegates' details be provided to AIDS Councils before the conference and that the individual Councils be encouraged to liaise with delegates as a means of introduction to the AFAO event. Councils could also, it was suggested, facilitate introduction between delegates from the same state/territory. It was suggested that because many delegates will be travelling a long way from home, sometimes for the first time, familiarisation with other delegates would help ease them into the conference. Another delegate suggested a 'buddy' system - so that delegates who have been to an Anwernekenhe event before can take on responsibility for showing a newcomer around. It was also suggested that there be a social event prior to the first day to help break the ice. While social

events can be difficult inclusions in conferences - often because conference funding agencies are reluctant to pay for them - future Anwernekenhe events may well benefit from the inclusion of a social event at the commencement of the event. It is likely such a social event would facilitate learning for newcomers.

On a more practical note, one delegate suggested that socialisation could be promoted through greater emphasis on communal eating.

#### 4.3 Suggestions about content

Overall, it would seem that the conference organisers struck the right chord in terms of the content. This is indicated by the positive feedback on the “relevance” of all sessions. Feedback on the degree to which sessions were understandable was also positive, however three delegates identified the need for some assistance in understanding content. One delegate called for greater explanation of acronyms, one for better explanation of research terms and another for a map of the health bureaucracy.

Delegates suggested that future conferences include sessions on nutrition and diet, more scientific information and research information, and more emphasis on strategic direction.

#### 4.4 Issues relating to format

There appeared to be some support for greater emphasis on workshops and informal gatherings with two delegates seeking more workshop sessions and another calling for “more time to yarn”. Similarly, two delegates called for more networking opportunities - one delegate seeking greater networking between Indigenous projects and another calling for greater networking with research.

#### 4.5 The role of AIDS Councils

There were several interesting suggestions concerning the role of AIDS Councils. One delegate sought greater involvement of AIDS Council employees in Anwernekenhe events, particularly those in senior positions. A second delegate called for the next Anwernekenhe to play a more formal role in scrutinising the performance of AIDS Councils in the area of Indigenous sexual health. Another participant suggested that the next conference include a forum for non-Indigenous people working against racism and a fourth suggested greater opportunities for non-Indigenous people working in the area to discuss their work - including project failures - possibly in the absence of Indigenous people.

#### 4.6 Indigenous content

One respondent called for more Indigenous delegates to attend the next conference and another called for more presentations from Indigenous people. A third participant called for the event to be better used to get information from the grass roots and suggested the conference be better used as an opportunity for focus testing of Indigenous resources and gaining input into the development of sexual health strategies. Another respondent suggested that the next conference include more Indigenous women and, in particular, Indigenous lesbians.

While most delegates supported the allocation of a specific day for Indigenous attendees only, one person commented that this should not be a feature of Anwernekenhe IV and a second respondent argued that the Indigenous-only day should be put at the end of the conference.

There was a specific criticism of the invisibility of Torres Strait Islanders at the event.

#### 4.7 Organisational

There was criticism of the scholarships program and a request that future programs be more accessible. There was also a suggestion that future funding include assistance in the provision of warm clothing for delegates.

## 5. Conclusion

It is reasonable to conclude that overall the evaluations were particularly encouraging and supportive of the conference program and events.

The program content was rated as highly positive. All sessions scored well in terms of relevance, clarity and accessibility, and cultural appropriateness. There were many positive aspects of the conference planning, including the ability and willingness of the conference planning committee to revise content for Days 2 and 3 according to concerns identified as the program unfolded.

Participants identified their favourite and less favourite workshops/sessions throughout the conference and it seems appropriate that the peer education and developing partnerships session was identified as the most popular component of a conference built around the theme “Strengthening communities through prevention, peer education and partnerships”. No single session appears to have been particularly problematic - while delegates had varied responses to sessions, no one session was listed as least favourite by more than three people and almost every session which was listed as somebody’s least favourite was the session most favoured by another delegate.

Conference organisers appear to have effectively measured community need with delegates generally supporting the length of conference and the reserving of one day for Indigenous gay men and sistergirls only. The venue was rated as very positive, offering participants a space to converge and to initiate discussion and action.

The evaluation forms clearly indicated that participants support the holding of Anwernekenhe IV and would attend another conference of this nature.

In conclusion, Anwernekenhe III represented a great achievement on the part of the conference planning committee and members of the national gay men and transgender/sistergirl community. The participants and organisers are to be congratulated on their significant contribution. It is obvious that this dedicated group of people have succeeded in setting a very high standard against which future events may be judged.

## CONFERENCE PROGRAMME - DAY 1

TIME	SESSION	PRESENTERS	PRESENTATION	CHAIR FACILITATOR
9.00 - 10.30 <b>Pelican Room</b>	Anwernekenhe III Opening	<p><b>Robert Smith</b> <i>Chair – AFAO National Indigenous Gay, Sistergirl &amp; Transgender Strategic Alliance for HIV/AIDS &amp; Sexual Health Promotion</i></p> <p><b>Ron Johnson</b> <i>Convenor Koori Gay, Sistergirl &amp; Transgender Social Support Group</i></p> <p><b>Will Shake Spear Dancers</b></p> <p><b>Don Baxter</b> <i>Chief Executive Officer – Australian Federation of AIDS Organisations</i></p> <p><b>Jill Gallagher</b> <i>Board of Directors - National Aboriginal Community Controlled Health Organisations</i></p> <p><b>Tiwi Island Dancers</b></p>	Anwernekenhe III official and cultural opening	Maurice Shipp
10.30 - 11.00	M/Tea			
11.00 - 12.30 <b>Pelican Room</b>	Opening Plenary <i>(A Changing Environment)</i>	<p><b>Colin Ross</b> <i>Qld Aboriginal &amp; Islander Health Forum</i></p> <p><b>Gary Lee</b> <i>Danila Dilba Aboriginal Medical Service</i></p> <p><b>Michael Costello</b> <i>Australian Federation of AIDS Organisations</i></p> <p><b>Robert Smith</b> <i>Chair – AFAO National Indigenous Gay, Sistergirl &amp; Transgender Strategic Alliance for HIV/AIDS &amp; Sexual Health Promotion</i></p>	A presentation of National Indigenous gay, transgender, sistergirl HIV/AIDS and sexual health initiatives that have been implemented since Anwernekenhe I and future directions	Neville Fazulla
12.30 – 1.30	Lunch			

1.30 – 3.00 <b>Pelican Room</b>	<b>Developing Partnerships &amp; Networks</b>	<p><b>Chris Lawrence</b> <i>Aboriginal Medical Co-op Ltd (Redfern)</i></p> <p><b>Colin Ross</b> <i>Qld Aboriginal &amp; Islander Health Forum</i></p> <p><b>Mark Saunders</b> <i>Australian Research Centre for Sex Health &amp; Society</i></p>	<p>- Here comes the 21<sup>st</sup> century (it's gonna be much better for a girl like me)</p> <p>- Formal &amp; informal partnership networks</p> <p>- Report on the Indigenous stream of the Sixth International Congress on AIDS in Asia &amp; the Pacific</p>	Maurice Shipp
3.00 – 3.15	<b>A/Tea</b>			
3.15 – 4.15 <b>Pelican Room</b>	<b>Treatment Care &amp; Support</b>	<p><b>Sam Barsah/Chris Lawrence</b></p> <p><b>Tony Creighton</b> <i>National Association of People Living with HIV/AIDS (NAPWA)</i></p>	<p>- Confronting nurse 'popper pill'</p> <p>- Report on the Indigenous male position of the NAPWA Board</p>	Neville Fazulla
4.15 – 4.30	Break			
4.30 – 5.30 <b>Pelican Room</b>	<b>Research – New &amp; Emerging Trends</b>	<p><b>Dr Jon Willis</b> <i>Australian Research Centre in Sex Health &amp; Society</i></p> <p><b>Professor John Kaldor</b> <i>National Centre in HIV Epidemiology &amp; Clinical Research</i></p>	<p>- Aboriginal &amp; Torres Strait Islander Futures</p> <p>- How do we collect HIV/AIDS data within Indigenous communities &amp; what we need do with that data?</p>	Mark Saunders

## CONFERENCE PROGRAMME - DAY 2

**Day 2 has been designated an Indigenous Gay Men & Sistergirl only day.  
For all other participants a half-day skills building workshop will be offered.**

TIME	SESSION	PRESENTERS	PRESENTATION	CHAIR FACILITATOR
9.00 - 10.15 <b>Pelican Room</b>	<p>AFAO National Indigenous Consultation Report &amp; Sexual Health Strategy Recommendations <b>Update</b></p> <p>This session will be conducted over three parts</p> <ul style="list-style-type: none"> <li>• Update</li> <li>• Breakout</li> <li>• Report back</li> </ul>	<p>AFAO National Indigenous Gay, Sistergirl &amp; Transgender Strategic Alliance for HIV/AIDS &amp; Sexual Health Promotion</p> <p>Robert Smith (Chair &amp; W.A) Peter Pinnington (Deputy Chair &amp; ACT) Shane Burgess (S.A) Vincent Strong (QLD) Michael Murray (VIC) Denis Ridgeway (NSW) Jacki Timpngwuti (N.T) Crystal Johnson (Sistergirl Rep) Mark Saunders (Research Rep)</p>	<p>An update on the implementation of the priority recommendations of the <i>AFAO National Indigenous Gay &amp; Transgender Consultation Report &amp; Sexual Health Strategy</i></p>	Michael Costello
10.15 - 10.30	M/Tea			
10.30 – 11.30	<p><b>Breakout</b> into groups</p> <p><b>Breakout discussion groups to consider and review priority recommendations</b></p>		<ul style="list-style-type: none"> <li>- Gay Men</li> <li>- Mature Age Gay Men</li> <li>- Youth</li> <li>- HIV Positive</li> <li>- Sistergirl</li> </ul>	<ul style="list-style-type: none"> <li>-Peter Pinnington</li> <li>-Corey Czok</li> <li>-Neville Fazulla</li> <li>-Crystal Johnson</li> </ul>
11.30 – 11.45	Break			
11.45 – 12.30 <b>Pelican Room</b>	Facilitators to <b>report back</b> on group discussions	<p><b>Peter Pinnington</b> <b>Corey Czok</b> <b>Neville Fazulla</b> <b>Crystal Johnson</b></p>		Michael Costello

### Skills Building Workshop (Day 2)

TIME	SESSION	FACILITATOR	BACKGROUND	LOCATION
9.00 – 10.15	History, Health & Harmony (Enhancing skills in working with Indigenous communities) Part 1	<b>Maurice Shipp</b>	This is an AFAO developed resource workshop that covers an overview of Indigenous History, Health and looks at ways in which working with Indigenous communities can be developed or increased.	Kingfisher Room
10.15 - 10.45	M/Tea			
10.45 – 12.30	Part 2			

12.30 – 1.30	Lunch			
1.30 – 3.00 <b>Pelican Room</b>	HIV Treatments Workshop	<b>John Day</b> <i>President- PLWHA Victoria</i>  <b>Neville Fazulla</b> <i>Life-Choices</i>  <b>Jim Arachne</b> <i>Complimentary Therapies Treatments Officer – Victoian AIDS Council</i>  <b>Jenny McDonald</b> <i>HIV Dietician &amp; Nutritionist – St George Hospital</i>	<p>An interactive workshop that will provide an update on new developments with treatments and also explore challenges that exist for Indigenous communities.</p> <p>This workshop will also look at complimentary therapies, diet and nutrition plus taking recreational drugs whilst on drug treatments.</p>	
1.30 – 3.00 Kingfisher Room	Developing a Sistergirl Resource		AFAO is currently developing an Indigenous Sistergirl Resource. This workshop will work on developing the theme concept and type of resource.	Kooncha Brown Michael Costello
3.00 – 3.30	A/Tea			

<p>3.30 – 5.00</p> <p><b>Pelican Room</b></p>	<p>Sexual Abuse Forum</p> <p><i>Please note this session requires separate registration.</i></p>		<p>Child sexual abuse is a prominent and urgent issue for Indigenous communities and one that can be controversial. Indigenous communities have not always agreed to what the best way to respond to this issue should encompass. Responses or lack of response at times have been criticised. This forum will provide space to allow discussion of this issue and ways in which it can be appropriately addressed and progressed.</p>	<p>Gary Lee</p>
<p>3.30 – 5.00</p> <p><i>Room to be notified</i></p>	<p>Indigenous Treatments Resource – Focus Testing</p> <p><i>Please note this session requires separate registration</i></p>		<p>This session will provide participants with the opportunity to workshop and focus test the AFAO Indigenous Treatments Resource.</p>	<p>Neville Fazulla Ross Duffin</p>

**CONFERENCE PROGRAMME - DAY 3**

<b>TIME</b>	<b>SESSION</b>	<b>PRESENTERS</b>	<b>PRESENTATION</b>	<b>CHAIR FACILITATOR</b>
9.00 - 10.30 <b>Pelican Room</b>	<i>Peer Education/Prevention &amp; Community Development</i>	<p><b>Crystal Johnson</b> <i>AFAO National Indigenous Gay, Sistergirl &amp; Transgender Strategic Alliance for HIV/AIDS &amp; Health</i></p> <p><b>H Tippo/B Leishman/W Mawudda</b> <i>Indigenous Project Officers - Queensland AIDS Council</i></p> <p><b>Kooncha Brown &amp; Stephen Darcy</b> <i>ATSI Project Officers – AIDS Council of NSW</i></p>	<p>- Community development initiatives between the Northern Territory AIDS Council and the gay &amp; sistergirl community</p> <p>“Ngalpun Yaw”</p> <p>- Current initiatives of the Indigenous Project at the AIDS Council of NSW (ACON)</p>	Mark Saunders
10.30 - 11.00	M/Tea			
11.00 - 12.30 <b>Pelican Room</b>	<b>New and Innovative Projects</b>	<p><b>Elizabeth Harvey</b> <i>Australian Intravenous League</i></p> <p><b>Jim Morrison &amp; Robert Smith</b> <i>WA Gay &amp; Sistergirl Support Group</i></p> <p><b>Rachel Tregonning</b> <i>Programme Support Manager – Indigenous Team (Marie Stopes International)</i></p>	<p>- Dancing in the Dark</p> <p>- Self Determination (The West Australian Gay &amp; Sistergirl Community Experience)</p> <p>- Developing Indigenous branded condoms</p>	Colin Ross
12.30 - 1.30	Lunch			

<p>1.30 - 3.30</p> <p><b>Pelican Room</b></p>	<p>Closing Plenary</p>	<p>All Chairs/Facilitators</p> <ul style="list-style-type: none"> <li>• Developing Partnerships &amp; Networks (<b>M Shipp</b>)</li> <li>• Treatment/Care &amp; Support (<b>N Fazulla</b>)</li> <li>• Research – New &amp; <b>Emerging Trends</b> (<b>M Saunders</b>)</li> <li>• ANICR&amp;SHS Recommendations Review (<b>M Costello</b>)</li> <li>• Sexual Violence Workshop (<b>G Lee</b>)</li> <li>• Peer Education/Prevention &amp; Community Development (<b>M Saunders</b>)</li> <li>• New &amp; Innovative Projects (<b>C Ross</b>)</li> </ul>	<p>Chairs/Facilitators will provide an overview of sessions and the recommendations from each of these sessions and workshops</p>	<p>Robert Smith Dermot Ryan</p>
<p>Afternoon Tea</p>				

**7.00 until Late**  
**Melbourne Koori Gay, Sistergirl & Transgender Social Support Group**

Presents

**OUTblack**

@ Mayfields  
103 Smith St  
Fitzroy

## *ANWERNEKENHE III - SUMMARY OF HISTORY PRESENTATION.*

*Colin Ross*

---

### **Introduction**

In this keynote address I will chronicle major events and issues that impacted on the Indigenous Australians' response to HIV/AIDS in the context of the Indigenous Gay community view point. I will talk about what happened in the Sydney community and how that influenced change through political and health action leading up to the release AFAO National Indigenous gay and transgender consultation report and sexual health strategy 1998. Clearly at the time AIDS Councils were perceived as, Not having much indigenous cultural awareness, did not know how to work with Indigenous PLWHA's, gay men and sistergirls and were seen as a non Indigenous gay men & HIV/AIDS organizations. By the same token ACCHS in the early days were perceived as being homophobic, lacking confidentiality and not being very user friendly towards indigenous gay men, sistergirls and PLWHA's. I will briefly discuss some of the positive attributes and dilemmas experienced by the AFAO indigenous gay men and sistergirl WP. I will make some points about discussions with other stakeholder and how that impacted on the direction the AFAO WP to 1998.

### **A number of key events & issues:**

- Similar to the US situation HIV/AIDS emerged in the mid 1980s in Australia as a major health and political issue amongst the gay community.
- HIV/AIDS had a devastating impact on young gay men, the impact was also experienced by our own Indigenous gay men, sistergirls and their community.
- Similar to the gay community, Indigenous gay men and sistergirls statistically have the highest rates of HIV/AIDS in our community 65% of positive Indigenous Australians' identified as gay and sistergirl. (Kaldor,1996).
- The National Aboriginal Health Strategy 1989 highlighted the concern of high rates of sexually transmitted diseases in the Indigenous community and expressed fears that this could be a catalyst for HIV/AIDS to enter our community.
- The Strategy also talked about at risk groups within the Indigenous population being Indigenous gay men/homosexually active men, youth, injecting drug users, women and Indigenous prisoners.
- The first National Aboriginal and Torres Strait Islander HIV/AIDS Conference held in Alice Springs in 1992 was almost a decade after HIV received national focus within the gay and mainstream media.
- The idea for this conference was initiated at the grass roots level by Indigenous gays, lesbians, their supporters and community controlled health agencies. There was considerable mobilization and the catch cry at the time was "HIV/AIDS is Everybody's Business", health promotion material was widely

circulated 'Condoman' out of Palm Island and the Bancroft Posters, on Education, Prevention, Care and Support and posters depicting messages for the Torres Strait Islanders.

### **In summary**

- The AFAO WP is influence change in HIV/AIDS and sexual health, other areas of social and strategic health policy, partnerships and service delivery, not only for indigenous gays and sistergirls issues, but for the indigenous community as a whole.
- As change agents it was important for us to inform the HIV/AIDS community sector at a National, State and local level that we intended to keep our issues on the agenda, that we need assistants in partnership to do it and this partnership must be balanced.
- Indigenous WP members in consultation with Indigenous gays and sistergirls will continue to lobby the government and community sector to support us in partnership.
- It is important the WP develop new ways of moving forward and fundamental to this is developing an atmosphere of openness and transparency in the operations and management of the WP and its partnerships dealings with other AFAO constituencies and jurisdictions.
- AFAO WP members lobbied in their own jurisdictions about our issues in relation to the employment of Indigenous HIV/AIDS Educators being employed in AIDS Councils.

The AFAO National Indigenous Gay, Sistergirl & Transgender Strategic Alliance for HIV/AIDS & Sexual Health Promotion (formally The AFAO National Indigenous Gay, Transgender- Sistergirl Steering Committee)

**Position Paper: Review & Amendments to the *Terms of Reference and Roles & Responsibilities* of the Strategic Alliance**

**Michael Costello**

---

**Introduction**

In February 2002, the National Indigenous Gay, Sistergirl & Transgender Steering Committee convened a meeting to review the committee's terms of reference. The terms of reference and roles and responsibilities were reviewed in response to recommendations from the Druett Consulting *Review of the Indigenous Gay & Transgender (Sistergirl) Project* and the contractual agreement between the Australian Federation of AIDS Organisations (AFAO) and the Commonwealth Department of Health & Ageing (CDH&A).

**Background**

AFAO's formal work in Indigenous HIV/AIDS and sexual health began in 1994 at Anwernekenhe I, the first national conference for Indigenous gay men, sistergirls and transgender people. The conference illustrated AFAO's role in response to the threat of HIV/AIDS to the Indigenous gay, sistergirl and transgender community.

Anwernekenhe I highlighted the need for a more strategic approach to HIV/AIDS and sexual health initiatives for the Indigenous gay, sistergirl and transgender community. As part of this approach, an Indigenous Gay and Transgender Working Party was formed to advise AFAO on matters relating to Indigenous HIV/AIDS and sexual health and to oversee the development of a national Indigenous project. To achieve this stage of development, the Working Party became the National Indigenous Gay & Transgender Steering Committee.

The Steering Committee helped to guide the establishment of AFAO's Indigenous Project in 1996. The Project was charged with responsibility for conducting national consultations with Indigenous gay men, sistergirls and transgender community members and HIV/AIDS - sexual health service provision to assess education, care and support needs.

In July 1998, Anwernekenhe II was held and the *AFAO Indigenous Gay & Transgender Consultation Report and Sexual Health Strategy* was endorsed and released. To guide and support the implementation phase, a new National Indigenous, Gay/Sistergirl Steering Committee was elected.

## **New developments**

Implementation of the *AFAO Indigenous Gay & Transgender Consultation Report and Sexual Health Strategy* provided significant achievements and shifts in the project's direction. During 2001 AFAO's Strategic Directions Setting Process was concluded, and AFAO members adopted the Statement of Directions 2000-2004. The statement includes recommendations relating to AFAO's future engagement with Indigenous Australians. Specifically, it is agreed that AFAO will continue to conduct work with Indigenous gay men and the sistergirl community. This area of work is identified as one of AFAO's four major areas of work.

The Druett Consulting *Review of the Indigenous Gay & Transgender (Sistergirl) Project* further supported this focus, with emphasis placed on policy development for increasing collaboration and mechanisms for input into the project's work.

In response, the former Indigenous Gay & Sistergirl Steering Committee, the AFAO Board and management developed what is now known as:

*A Changing Environment Paper* - AFAO's response to the review of the Indigenous Gay, Transgender (Sistergirl) Project including a "How To Action Plan".

*A Changing Environment* sets out a broad response to building on the strengths and achievements of the project and ways in which new developments can be pursued. The paper acknowledges that there is still work to be done in the area HIV/AIDS and sexual health for the Indigenous gay and sistergirl community and new initiatives must be considered to sustain any future responses.

'Ownership in Partnership' is the model supported in progressing the implementation of the Indigenous Project, which will place greater emphasis on increased Indigenous input through joint collaboration into decision-making processes. This is further supported with project staff having a more senior role within AFAO. Reviewing and amending the roles & responsibilities and terms of reference became the first step in this process and it is envisaged these amendments will guide the process.

## **Amendments**

In a unanimous decision the committee voted to make the following amendments to the terms of reference and roles and responsibilities.

Membership will be reflected by experience and skills in HIV/AIDS & sexual health as compared to state and territory geographical location;

Membership to the Strategic Alliance to be selected through expression of interest;

Indigenous membership reduced from current numbers to one greater than the ex-officio representation. This will maintain the majority Indigenous community voice;

Inclusion of ex-officio positions, these positions will be invited onto the Strategic Alliance;

Guiding principles for the terms of reference around advise and input of Strategic Alliance;

Change of name.

### **Committee Name Change**

The National Indigenous Gay, Sistergirl & Transgender Steering Committee agreed a change of name to the committee would better reflect the new committees objectives. The new committee hereafter would be known as the National Indigenous Gay, Sistergirl & Transgender Strategic Alliance for HIV/AIDS and Sexual Health Promotion.

### **Timeline**

- March 1 - Steering Committee becomes Strategic Alliance  
membership - Strategic Alliance set criteria for
- March 15 - Call for expressions of Interest  
- Media/Promotion
- May 17 - Anwernekenhe III (committee retires, transitional reference group starts and discussion of possible members)
- June 15 - Expressions of interest close
- June 22 - Interim reference group selects Indigenous community members of advisory group
- July - New Strategic Alliance meets

### **Interim Committee**

The current Strategic Alliance will retire at the completion of Anwernekenhe III. To guide the process of crossover between committees and to select the new Strategic Alliance, an interim committee has been established.

The interim committee is:

Two members of the current Strategic Alliance (these members cannot express interest in the new Strategic Alliance)

AFAO senior Project Officer

Two community members (also unable to express interest in the new Strategic Alliance)

## **'Here comes the 21st Century, it's gunna be much better for a girl like me' Developing Effective Aboriginal and Torres Strait Islander Sexual Health Partnerships and Networks.**

**Chris Lawrence**

---

There are low numbers of HIV positive Aboriginal persons in Australia. This does not mean that health services and authorities should consider HIV infection to be a low Aboriginal health priority. What it does mean is that we should be continuing to incorporate up dated and relevant information into the health work force (in particular Aboriginal sexual health workers and educators) community development programs, education material and our care and support services to maintain these low figures. Keeping up-to-date with current research findings also allows for appropriate funding applications to be sought for program and service delivery.

Nationally, there are, at last count, 155 known Aboriginal people infected with HIV/AIDS. Most of these people are homosexually active males and they reside in Sydney NSW. They live here for many reasons including the greater tolerance of homosexual lifestyles in some parts of Sydney. As is often the case in non-Aboriginal communities, homosexuality and HIV/AIDS can be problematic issues in many Aboriginal communities.

Globally there are a number of difficult and complex issues that affect many people living with HIV/AIDS. In Australia, while most HIV medications are subsidised under the Pharmaceutical Benefit Scheme (PBS), many HIV positive people, in particular, Aboriginal HIV positive people still find it difficult to comply and manage their medications and therefore do not utilise this service to its full advantage.

Lack of a stable income and essential human necessities, such as, education, affordable housing and household goods (refrigerator) limit many Aboriginal HIV positive people's abilities to maintain HIV medication compliance and clinical follow-ups. Social issues, such as, alcoholism, injecting drug use, criminal background also impacts on many Aboriginal people in the community. Mental health and other health complications are also attributes.

The main limiting factor in the capacity of Aboriginal people to participate in prescribed drug treatment is the fact that they cannot afford to purchase medications. This means that while we have sophisticated recall systems, all our efforts to implement evidence - based medicine can break down. Extension of the S100 scheme could yield very substantial benefits very quickly and for little cost.

According to Aboriginal cultural theory, Aboriginal people have two ways of dealing with gender issues: Men's business and Women's business - including sexual issues. Therefore, sexuality issues such as homosexuality are dealt within a framework that is not consistent with acceptable sexual practices. For example, anal sex between two males does not exist as a concept within Aboriginal human creation philosophies and therefore does not require attention. Since the number of HIV positive Aboriginal people is low, thus far, there has been no significant adverse outcome arising from this aspect of Aboriginal cultural analyses of sexuality. However, it is important to

guard against complacency. Similar beliefs amongst many of the world's Indigenous communities may have contributed to the spread of HIV.

We know that there are millions of people infected with HIV or living with AIDS in African countries. Canadian Aboriginal people also have high numbers of its populations infected with HIV and injecting drug use has been a very significant mode of transmission. Cultural beliefs may also inhibit many prevention, intervention and harm minimisation programs from being developed and implemented.

Currently, human trials of new anti-retroviral are operating within Australia and within the next few years, human HIV vaccine trials will commence. The outcomes of these trials will influence the future of HIV and may have a profound impact on the life expectancy of HIV positive persons. It is important to emphasise that the world's Indigenous communities are also the world's poorest communities. It is imperative that those communities are able to access new therapies so that their needs can be fully addressed.

The 1999 National Indigenous Australians Sexual Health Strategy Mid-Term Review acknowledged that 'In States and Territories where there is no real clear identification of Aboriginal sexual health priorities or a strategic framework to guide allocation of resources, State and Territory Forums should consider laying down appropriate guidelines. Forums which have not yet established a sexual health committee representing the various partners may wish to consider doing this'

Most States and Territories are now in discussion and negotiation to implement state/territory sexual health committees. In NSW for example, talks between the Office of Aboriginal Torres Strait Islander Health, the secretariat for the National Indigenous Australians Sexual Health Committee, the Aboriginal Health Medical Research Council and the AIDS Infectious Disease Branch of NSW Health have occurred with positive outcomes. However, community consultation and participation from sexual health workers and those at high-risk should be part of the process from the beginning.

NSW Health has since appointed a committee to meet in June this year to oversee the implementation plan in NSW. To be part of implementing this plan, a number of us through AIDS Council Of NSW and the Aboriginal Medical Service in Redfern, have organised our own NSW Aboriginal and Torres Strait Islander PLWHA, gay, lesbian and transgender/sistergirl, Advisory Group. This group will not only have two seats on this committee, but will also provide input on a number of other government initiatives. We would also encourage other groups to form their own advisory groups in their states and territories and take leadership of the issues in their local area. Take control rather than be controlled.

In NSW there are a number of concerns with the current funding structure of Aboriginal Sexual Health Workers. As it is, Aboriginal Sexual Health Workers are employed under different Award schemes, depending on government or non-government sectors. NSW Health, AIDS Infectious Branch receive Aboriginal sexual health dollars direct from the Office Aboriginal Torres Strait Islander Health to distribute to its agencies and NGO's, including AMS's, to employ and deliver sexual health programs. This arrangement was agreed to by the Partnership between the

Aboriginal Health & Medical Research Council of NSW and the AIDS Infectious Disease Branch of NSW Health.

The main concern with this arrangement is that there is no clear support mechanism for Aboriginal sexual health workers. The only support structure that exists is the one that workers create for themselves through their own networks. While we have an Aboriginal sexual health workers network meeting once a year it is not enough to just listen to one another's stress because of work demand and overload.

Depending on the award scheme, Aboriginal sexual health workers primary role is to provide community people with safe sex education and develop prevention messages for HIV/AIDS. For those Aboriginal sexual health workers trained and employed to carry out clinical testing and screening for STI's, their jobs can become even more pressured. At the moment, in NSW Aboriginal sexual health workers are employed to provide education and develop safe sex campaigns and act as a referral network. There is a call from Sexual Health Workers to do PCR testing as part of their roles. This needs to be seriously considered with extreme caution, but it should be considered. My concerns are that the award schemes may take longer to change and implement and that while this process is going through the red tape, workers will continue to be underpaid for their new skills.

Most clients that present to Aboriginal sexual health workers in NSW are already HIV positive. Many identify as gay or bisexual Aboriginal males with drug and alcohol dependencies. They also come from a background of sexual abuse/assault, prison history and usually have a mental health condition. Unemployment, homelessness and poverty also contribute to their situation. Sex work is often their only means of financial income and support.

The problem for the sexual health worker is that their role now becomes multitude with little or no resources to support their efforts for the client. With many clients not wishing to disclose their HIV status the task for the worker becomes even more challenging as they weave their way through the hundreds of bureaucratic tentacles hoping that someone will help them. Sending our clients around in circles only disempowers them.

Re-coordination of sexual health programs may resolve some of these problems. Some of our Aboriginal sexual health workers only want to concentrate on developing appropriate safe sex messages through promotion campaigns to the community. Others wish to develop community programs and education workshops, while some are confident to provide client support and counselling. Management of these programs needs to ensure that they are placing the right person in the right job and encourage continuing professional development. They also need to understand that sexual health workers cannot work in isolation; support from other workers is essential.

Changes to the funding arrangement may also help. I know this is a huge policy headache and people think it's too political, but I would encourage people to remember the day Aboriginal people were given citizenship rights and the fight that was fought to make those changes happen - it can happen.

## Recommendations:

- Continue developing mechanisms to make sexual health a priority across the health sectors
- Develop better communication avenues to state and national sexual health representatives
- Link and invite sexual health workers to be part of state and national initiatives - through the state/territory Coordinators as well as Partnerships
- Consider a more effective sexual health funding arrangement that allows sexual health workers participation in decision making at the state and national level as well as on the ground
- Develop a national Aboriginal sexual health workers network to provide input into national policy and strategies
- Develop a standard Award Scheme for Aboriginal sexual health workers that create career pathways & opportunities e.g. managers
- Create funding opportunities for sexual health workers to research sexual & social behaviours in Aboriginal communities as part of their professional development
- Hold a National Aboriginal & Torres Strait Islander Sexual Health Workers Forum to hear the concerns and issues in a constructive way

## **"Work with us, not for us nor on our behalf "**

**Mark Saunders**

---

I'd like to acknowledge the traditional owners of this land as well as acknowledge all of you.

I'm pleased that I've been asked to present in this session. Anyone who knows me, will have often heard me say that any partnership involving community must place the community at its centre. Some of you will also have heard me describe partnerships that involve our community, as nothing more than fingertip partnerships. What I mean by a fingertip partnership is literally that - that we are hanging on to the fingertips of those who place themselves in a far more senior position than us in these arrangements. Often the justification for this is that they hold the expertise and the purse strings. I hope by the end of this talk today you will understand exactly what I am referring to here and why it is important that we come together at this third Anwerkenhe to reimpose and reinforce our position at the very centre once and for all.

In this presentation I'll be reflecting on some of the partnerships formed and the potential partnerships that we as Aboriginal and Torres Strait Islander people have been and could be involved in. The very term partnership, I believe, is often a very fluid and sometimes inappropriately applied term. Partnerships involving or more precisely, partnerships formed on behalf of Aboriginal and Torres Strait Islander gay men and sisters, can result in highly disempowering outcomes for our communities.

The partnership between AFAO and the Commonwealth is a good example of this. Where is the community in this partnership? How can the role of Aboriginal and Torres Strait Islander gay men and sisters be taken seriously in this relationship when we are relegated to nothing more than consumers of service delivery? If you consider this, we are totally removed from this partnership - the partnership is now between AFAO and the Commonwealth.

Why do we have partnerships? Rather than a word on paper, I'd like to think that partnerships, particularly in the HIV/AIDS tradition, are relationships that put grass roots community based and owned responses into practice.

In this way, partnerships are supposed to be founded upon and strive to achieve a sense of equality between all parties, including most importantly the community it seeks to serve. Even the partnership so patronisingly formed on our behalf between AFAO and the Commonwealth is not equal. The Commonwealth recognises that as the funding body it ultimately controls the partnership and being financially dependent on the Commonwealth, AFAO is definitely the junior partner. In the truest sense of the word, this is not a partnership - it is nothing more than a funding agreement. Yet we, the community, are expected to be thankful for this so-called partnership, when in fact, it is the Commonwealth's duty to fund this work.

This has serious implications for the community's capacity to independently further our own interests by taking advantage of opportunities. Which brings me to last year's

International Congress on AIDS in Asia and the Pacific (the sixth regional AIDS conference), which was held here in Melbourne in early October.

For the first time, an ICAAP presented a designated Indigenous and Ethnic Minority Communities track. This was a deliberate attempt to give greater profile to HIV/AIDS issues affecting indigenous and ethnic minority communities, to ensure a specific area in the program devoted to these issues and to give delegates from indigenous and ethnic minority communities across the Asia Pacific region a defined space to discuss their issues.

Efforts to form an organising committee for this track did not become operational until only four months before the Congress and a committee consisting of myself, Michael Costello, Bev Greet and Neville Fazulla and Jon Willis was formed.

A lack of promotion of ICAAP especially amongst Australia's Aboriginal and Torres Strait Islander communities, resulted in almost no scholarship applicants from indigenous and ethnic minority communities.

No designated funding had been pursued to support the attendance of indigenous people or the costs of speakers for program purposes. A successful funding submission by the committee resulted in a grant from the Australian Government's Office of Aboriginal and Torres Strait Islander Health (OATSIH). This grant, as well as monies already present for the general ICAAP program was utilised to fund the track and the attendance of indigenous delegates. This resulted in the largest attendance of indigenous people ever at an international HIV/AIDS conference. Under the circumstances, where time to organise the attendance of delegates, the committee used its own links to various (informal) networks to bring in delegates. Hence, there was not a consistent application and/or selection process applied and while a reasonable mix of community, health workers, academics and PLWHA was achieved, a more rigorous, less adhoc process, commenced long before the Congress would be highly desirable for the next ICAAP. Such a process would give greater guarantee to the appropriateness and diversity of delegates and maximise the possibilities of feedback from the Congress reaching more communities.

It is essential that specific funding and resources be set aside for the attendance of indigenous and ethnic minority delegates and the organization of the Indigenous and Ethnic Minority Communities Track for the Seventh ICAAP which is due to be held in Kobe, Japan in late 2003.

Twelve months before the Seventh ICAAP however, it would be beneficial to stage a Regional Forum for Asia-Pacific Indigenous and Ethnic Minority Communities to mobilise these communities to organise for the Seventh ICAAP. Ideally, a regionally based committee could emerge from this forum to drive the organization of the Seventh ICAAP's Indigenous and Ethnic Minority Communities Track. This should involve the organisers of the Seventh ICAAP and be designed to assist those organisers in continuing the track at the Kobe Congress. It would also act as a preliminary awareness raising and recruitment exercise for support, presenters and attendees at the Seventh ICAAP track well in advance of the event. This, along with guaranteed funding, would go some way to alleviating the time constraints experienced by the track's organising committee at the Sixth ICAAP. The AFAO project is ideally placed to organise such a gathering.

Funding sources in other countries besides Australia as well as international sources such as relevant sections of the United Nations and other international NGOs should be investigated and urged to support these activities well in advance of the next ICAAP.

One of the program highlights was a special forum organised to facilitate the formation of links between gay indigenous delegates and gay and lesbian organisations involved in HIV/AIDS work throughout the region. This forum had been designed to link gay, lesbian, bisexual and transgender indigenous Australians with gay, lesbian, bisexual and transgender activists and organisations from the Asia-Pacific region. Several organisations from the Asia Pacific Network of gay, lesbian, bisexual and transgender communities, AP-Rainbow, including OCCUR from Japan, LEAP from the Philippines and GAYa Nusantara from Indonesia, provided introductions to their organisations in a bid to facilitate communication between these groups and indigenous Australians.

The success of a conference track such as this requires an understanding of and an ability to work with the access problems evident around indigenous issues in the region. Unless heavy, deliberate promotion of the Congress is made to these communities it is unlikely they will become involved. The task of including these groups clearly cannot be left to the non-indigenous majorities of many countries, who themselves do not see indigenous issues as a relevant HIV/AIDS priority or even deny the existence of their indigenous communities.

There is a genuine lack of political will across the region (and indeed the world) around these issues. The AFAO project must take a far more proactive role in ensuring our involvement and the profile of our issues and the issues affecting our indigenous brothers and sisters throughout our region at such gatherings.

In many countries within the region, there are significant barriers to even the recognition of indigenous status and further, within the HIV context, many countries do not record data on the basis of the ethnicity or indigenous status of those infected or at risk. This makes quantifying the epidemiological extent of HIV/AIDS amongst these populations very difficult.

Language, geographic location and dispossession of land further compounds these difficulties. Locating indigenous peoples in border refugee camps and tribal contexts, especially those who can speak in English on HIV/AIDS is a very difficult task.

As such, ICAAP should build on the role it has played in profiling these issues at the Melbourne Congress. The challenge is not only to include these communities and their issues within the program but to raise awareness of the importance of HIV-related work on indigenous and ethnic issues across the region and amongst NGOs and the regional HIV networks etc. These networks are known as the Seven Sisters and consist of:

- AP-Rainbow, the gay, lesbian, bisexual and transgender network with whom we held the forum at ICAAP I mentioned earlier;
- the Asia Pacific Network of People Living with HIV/AIDS or APN+ (APN plus);
- Coordination of Action Research on AIDS and Mobility or CARAM-Asia, a group of NGOs working on migration issues in relation to HIV/AIDS;
- the Asia Pacific Network of Sex Workers;

the Asian Harm Reduction Network, an HIV/AIDS organisation working on drug use issues;  
the Asia Pacific Council of AIDS Service Organisations (or APCASO), a network of community-based AIDS services; and  
the AIDS Society of Asia and the Pacific, a well-resourced group of individuals committed to regional HIV/AIDS work who are well linked to UNAIDS and are driving force behind each ICAAP.

A meeting of government ministers from throughout the region convened by Australian Foreign Minister Alexander Downer alongside the ICAAP produced a commitment to provide core funding for these seven regional networks for the next three years. This means that these networks will be a site of significant, funded activity in the next few years and now have a momentum behind them that presents a critical opportunity for us to participate.

The AFAO project, which has unique access to these organisations, the broader global networks they link with and the meetings they participate in should be playing a much greater advocacy role in advancing our participation and our relevance within them.

The following recommendations were made by delegates attending the Indigenous and Ethnic Minority Communities Track:

That there be a continuation of the Indigenous and Ethnic Minority Communities Track at the 7th International Congress on AIDS in Asia and the Pacific in Kobe, Japan in 2003.

That resources be put aside to support delegates from these communities to attend the 7th ICAAP.

That ICAAP support the indigenous people of the region in their struggle for recognition (including by and within developed nations of the region) as populations at risk of HIV/AIDS infection who generally experience health conditions similar to the developing world regardless of geographic location. That this Congress supports the staging of a satellite Indigenous and Ethnic Minority Communities Forum that substantially links with other community forums at the 7th ICAAP.

That the participants of this final plenary of the 6th ICAAP acknowledge and support the ongoing presence and involvement of their brothers and sisters from indigenous and ethnic minority communities, especially those living with HIV/AIDS.

The AFAO project has a responsibility to ensure that these recommendations are acted upon and advocated for.

There is considerable value in presenting a designated indigenous and ethnic minorities track, in terms of providing specific space for such groups to speak for themselves, network and discuss and compare their issues. However, there are potential drawbacks. A designated indigenous space within the program establishes the possibility of delegates completely avoiding indigenous issues and while substantial energy was invested in establishing the Indigenous and Ethnic Minority track, the presence of this type of material in the rest of the program was incidental. It would be highly desirable for a particular effort to be made to include indigenous and ethnic minority content elsewhere in the program, so that wider comparisons and awareness raising can take place and greater incentive exists for indigenous delegates to attend other sessions as well. In this way, the track can work as a stand-

alone part of the program while also having relevant coverage within the rest of the program.

Given the increased profile awarded to issues affecting indigenous and ethnic minorities at the Sixth ICAAP, it would have been desirable to have a focus on this subject within the main plenaries. This would be a very real way that the next ICAAP could further build on this profile.

Significant time needs to be invested in accessing indigenous PLWHAs and affected communities (such as men who have sex with men, transgendered people, sex workers and drug users) to participate in the ICAAP. No HIV/AIDS focused regional networks and very few national or even local organisations for indigenous peoples exist in the region, making including these populations very difficult. Further, in many areas of the region, such cultures exist as displaced populations in refugee settings or in tribal environments. Language presents a significant barrier to these people's participation and further consideration needs to be given to potential flexibility on this issue. Greater focus on skills building amongst this track would be a logical means of compensating for the language and literacy issues faced by these populations.

Given the little amount of activity in this area, AFAO should play a leadership role in encouraging the formation of a regional HIV-related network for indigenous people and ethnic minorities. There have already been indications, emerging from the Sixth ICAAP, that the AIDS Society of Asia and the Pacific, one of the key sponsoring bodies of the ICAAP gatherings, is prepared to lend practical support to forming such a network.

The Sixth ICAAP's Indigenous and Ethnic Minority Track was particularly successful in drawing together Australian indigenous people and the Maori population of New Zealand - it was these two populations that were most represented in terms of attendance and presentation. One of the track's recommendations, that indigenous people be recognised as experiencing health standards and HIV vulnerability comparable to the developing world, should also be matched by a recognition that indigenous peoples in developed nations nonetheless have greater potential access to significantly more resources than similar populations elsewhere in the region. This means that there exists both the potential and the responsibility to play a leading role in drawing other indigenous populations into the ICAAP.

Further consideration should also be given to including indigenous or first cultures from outside the region, particularly North and South America, where the parallels between the Asia-Pacific region are perhaps strongest.

There also needs to be much greater involvement by our people in the Regional HIV Positive Forum and the Community Forum - two key community events that take place alongside each ICAAP conference. One of the most effective ways of achieving one of the track's principle aims of drawing indigenous people and an awareness of their issues in relation to HIV/AIDS into the ICAAP and its associated networks would have been far greater participation by indigenous people in these Forums. Facilitating this involvement should be a joint responsibility of the AFAO project, the ICAAP organisers, the regional networks involved in staging these Forums and the indigenous and ethnic minority delegates themselves. Well-linked, cross promotional

efforts between the Indigenous and Ethnic Minority Communities track and the Community and HIV Positive Forums would go some way towards encouraging this.

An area of content that needs to be much improved upon is that of treatment and care. There are real and largely unaddressed issues of cultural appropriateness and scientific integrity involved in indigenous approaches to non-allopathic treatment and community-based care. These issues should be explored in future ICAAPs. Sound scientific analysis of the effectiveness of non-allopathic treatment approaches and evaluation of models of community-based care must be given some profile within the track as critical treatment and care issues for indigenous and ethnic minority communities.

Broad issues of land rights and dispossession also need greater specific focus as its consequences heightens HIV vulnerability through mobility, poverty and lack of political rights and self-determination. As such the track needs to have an overt political focus and should link in some ways to the role governments play in the ICAAP - political leaders need to hear what emerges from a track such as this.

There should also be some endeavouring to highlight culture and the role it plays or can play in HIV/AIDS prevention and education amongst indigenous and ethnic populations. The survival and maintenance of culture is crucial in this issue and should be profiled in future international conferences as fundamental to successfully responding to HIV amongst these communities. This most critically demonstrates the importance of staging a track such as this: while HIV/AIDS poses a threat to millions of lives across the region, in the context of indigenous and ethnic minority populations HIV/AIDS poses a threat to the very existence of particular cultures and ethnicities of human beings. In such a way, ignoring or marginalizing these populations amounts to forums like ICAAP and organisations like AFAO complying with the extinction of entire cultures. AFAO should also be playing a leading role in encouraging UNAIDS and comparable organisations to take this issue seriously.

AFAO is well linked to the regional community networks that are key participants in gatherings like the ICAAPs. Given the difficulties we have experienced with our domestic partnerships, having Anwerkenhe involved as an active, participating member in these networks would go a long way to strengthening our position domestically and enabling us to draw upon the support, knowledge and resources of these networks. Perhaps an elected Anwerkenhe group could be formed from this conference to participate in these networks and advocate for our inclusion in HIV regional development.

I'd like to give a recent practical example of the way these networks can advocate for one another. Within the last six months, the South Korean community has been mobilising against government plans to censor and block access to gay, HIV/AIDS and safe sex Internet sites, essentially on the grounds that they encourage homosexuality. Upon hearing of these plans, Korean gay groups immediately sent an alert through the AP-Rainbow network that resulted in the relevant government department being flooded with expressions of international concern. AP-Rainbow members also gave technical assistance to Korean gay organisations in filing a lawsuit against their government. Within a few weeks, the Korean government reversed its decision and announced its reversal not through Korean media outlets but by issuing a press release internationally (notably written in English, rather than

Korean). It is widely recognised, even apparently within the Korean government, that the international pressure and indications of support for gay and lesbian Koreans that they received was the primary motivator in reversing their decision.

This is an avenue and an opportunity that has not been explained to us or made available to us and it is an important tool for us to expand our support base to the regional level. Placing ourselves within this broader context, I think, will have significant benefit for our unity at the national level. It is our disunity that helps to destabilise and fracture the very foundation that we as a community sought to build our HIV response on and gives greater licence for others to take control out of our hands. It would help give us a greater sense of being an independently functioning community-based network, viewed as such by overseas countries, and that can only strengthen our position within our own domestic partnerships. It would help us protect our culture, our right to self-determination and help us build our profile internationally. I am making these suggestions as a practical means of us moving beyond the fingertip partnership we are currently experiencing. I would ask that some serious consideration be given to these ideas and that each of you think in terms of recommendations from this session about practical ways that our AFAO indigenous project, and more broadly, other sections of the AFAO secretariat and relevant parts of the AFAO membership, could assist us in driving forward these plans.

## **Breaking The Silence**

### **Indigenous, Gay, Transgender, Sistergirl Sexual Abuse Workshop**

**Gary Lee**

---

#### **Some Background**

For Anwernekenhe 2, held from 7-10 July 1998 in Queensland at Thunder Park, Tambourine Mountain it was planned that one of the workshops to be held would, for the first time, be on 'child sexual assault'. The then Australian Federation of AIDS Organisations (AFAO), Indigenous Gay and Transgender Project Steering Committee (steering committee) made this decision. The steering committee's decision was based on one of the major findings of the AFAO *National Indigenous Gay and Transgender Consultation Report and Sexual Health Strategy 1998-2000* (the Report) which was child sexual assault. Launched and unanimously ratified at Anwernekenhe 2, the Report clearly illustrated the prevalence of sexual abuse perpetrated on Indigenous gay and transgender/sistergirls. Also, the steering committee itself shared a broad knowledge, understanding and personal experience of sexual assault in childhood and for many, and well into adulthood. These two factors were the catalyst for a collective desire to start directly addressing our needs and future concerns regarding the sexual assault experienced by so many of us as Indigenous gays and transgender/sistergirls. In many respects this workshop was the genesis for us in taking control of this issue, and making the first steps forward towards 'breaking the silence'.

The workshop proved to be a very moving yet empowering meeting. What we had here, and perhaps for the very first time, was a formalised healing forum where participants could discuss and share their thoughts, views and experiences on childhood sexual assault in a safe, supportive and non-threatening environment. Response to the workshop was overwhelming, not just from the point of view of the high number of delegates who participated, but it was also due to the outpouring of personal recollections that came forth. Some of these recollections had been suppressed for many years and the workshop was still well underway while the others had ended for the day. Of the five major recommendations that came out of the Child Sexual Abuse workshop number three states; 'Cultural respect requires that we proceed cautiously with this issue, but silence is not the answer' (Anwernekenhe 2, Conference Report, 1998: 5). It was clear to the steering committee then that at the next Anwernekenhe conference, sexual abuse would feature as prominent agenda item.

#### **Anwernekenhe 3**

Four years down the track on 15-17 May 2002 in Melbourne at Anwernekenhe 3, Indigenous gay, transgender/sistergirl sexual abuse indeed featured prominently. A specific closed workshop, requiring separate registration and open only to gay and transgender/sistergirl delegates, was conducted. The hope was that the outcome(s) from this workshop would result in recommendations that would take our sexual abuse issues that one step further towards the 'taboo line', the one we need to step over if we are ever to progress this issue to the wider community. Until that line is crossed

and until we break that silence, nobody else is going to start doing anything about the widespread sexual abuse of Indigenous gay and transgender/sistergirls occurring in this country. We have to continue that momentum from those first tentative steps taken at Anwernekenhe 1 in 1994 at Hamilton Downs in Central Australia. Eight years down the track the Anwernekenhe 3 sexual abuse workshop again proved to be both timely and very empowering.

### **The Workshop**

It was hoped by the AFAO Indigenous Conference Organising committee that the Anwernekenhe 3 sexual abuse workshop would provide recommendations that would help progress our sexual abuse concerns 'to the next level'. In our terms the next step started with the inclusion of an Indigenous sexual abuse workshop on the agenda of the National Gay Educator's Conference to be held two weeks after Melbourne. It was hoped to advance our issues further in conjunction with support from the wider gay and transgender HIV and sexual health sector.

The Anwernekenhe 3 workshop had a high representation of elder gay men, sistergirl and tradition-based delegates from remote communities. It was decided that 'sexual abuse' was the term we wanted to use rather than 'sexual violence' or 'sexual assault'. Participants were arranged in a seated 'circle of healing', with the freedom to take the workshop and shape it in the way they felt it should go in. This worked successfully and again there was a very emotional, at times funny, but mostly moving and very poignant series of disclosures and outpouring of support. One younger delegate left the workshop in the early stages but all others remained to participate. Some sharing was done for the first time, as in one case after almost forty years of denial. The three-hour session ended with a beautiful healing song, devised and sung in language by the Tiwi sistergirls that both touched and empowered all of us in the workshop that day. A most culturally appropriate and fitting end.

### **Recommendations**

The structure of the workshop consisted of a healing circle. As facilitator my role was to guide the participants in the direction they so chose the workshop to go in. Discussion of possible recommendations came at the end of a very emotional three hours and final decisions were made unanimously and fairly quickly. Resulting from the workshop were the following two recommendations:

(1) That AFAO, in conjunction with the Commonwealth, instigate a national Indigenous gay, transgender and sistergirl sexual abuse report, and,

(2) That AFAO conduct a one-two day 'sexual abuse' forum, in conjunction with the AFAO Indigenous Strategic Alliance, to formulate such a project report, or boundaries thereof, which spotlights related sexual abuse, all those things we don't really like to talk openly about like; suicide, domestic violence, incest, substance and alcohol abuse.

The very nature of the recommendations indicates a high Indigenous gay and transgender/sistergirl concern for a wider recognition of and response to our sexual abuse issues. It is up to us to take this issue forward and to push or nudge it over the taboo line as mentioned before. That there are only two recommendations and these are solely concerned with a much broader approach and community response. It

also demonstrates our commitment and willingness to ‘cross the line’ or, as stated earlier, to start our own journey towards ‘breaking the silence’.

### **Conclusion**

Our workshop on sexual abuse was about ‘breaking the silence’, and about giving ourselves permission to talk about our experiences, without feeling like there was something wrong with us. It is also about the community acknowledging that there *is* a problem. We hope it will force the community to confront the reality of just what is going on because it is not just our issue it is a community one.

As children, gay, transgender/sistergirls in all societies have been and continue to be sexually abused. This can take many forms, from some types mentioned earlier, to many other kinds, like psychological and emotional abuse. Much of it takes place in our childhood or youth, but it can and still does occur in adulthood. Sexual abuse is not about sex. It is about domination, exploitation and humiliation many times by entrapment or through coercion, usually in order to make someone else feel stronger. It is about power and control. There have been few if any specific statistics collected, and even less social research conducted on Indigenous gay and transgender/sistergirl sexual abuse. In recent times, the calls for recognition of and action against Indigenous heterosexual abuse have risen around the country, largely through the initiatives and tireless efforts of Indigenous people themselves, with various levels of support from state and federal governments. It’s now time that we as Indigenous gay, transgender/sistergirl members of our communities gain the same levels of support for the sexual abuse issues facing us today. The cultural, social and emotional well being of our communities depends on it.

## **Dancing in the Dark - A look at Injecting Drug Use and the Transmission of Blood Borne Viruses in Indigenous Communities**

**Elizabeth Harvey**

Education Project Officer – AIIVL

---

Nationally Based Hepatitis C Peer Education Project

### **Who is AIIVL?**

Until recently AIIVL was known as Australian Intravenous League (AIVL) but now we are the Australian Injecting and Illicit Drug Users League (AIIVL), to be more inclusive and realistic about current work in the field

AIIVL neither promotes nor condones the use of illicit drugs; rather AIIVL seeks to provide accurate information that will help drug users make safer choices.

### **What does AIIVL do?**

- ? AIIVL provides education and prevention information to injecting drug users about blood awareness, blood borne viruses and safer injecting practices.

AIIVL does this in the hope of keeping injecting drug users from being infected or re-infected with blood borne diseases like hepatitis B, hepatitis C and/or HIV/AIDS.

AIIVL's member groups contribute to & distribute information about issues around illicit drug use.

### *AIIVL's principals of peer education:*

1. the support of information sharing within organic networks of people who inject drugs, respecting the knowledge, skills and experience that drug users already have;
2. less emphasis on the 'correct way to inject' or other pre-determined messages, instead focusing on enabling users to define their own issues and develop their own solutions;
3. dependence on the importance of the cultural and situational context of injecting, which may be unique to each social network;
4. the provision of information in a way that enables other users to pass on that information;
5. the sharing of power and responsibility for decision-making between drug users, rather than a formal structure that places peer educators (or project managers) in a position of authority and therefore outside of the group;

6. is not focused exclusively on outcomes, and equally values the process of learning and self-defined skill development, capacity building, empowerment and participation; and
7. follows a process of learning that is owned by those doing the learning, including ownership of the budget, reporting and other group processes.

### **AIVL's National Hep C Campaign**

The AIVL Education Program developed a series of national resources on safer injecting, cleaning fits and other useful information and service directories for injecting drug users.

AIVL's Education Program is currently targeting resources for specific populations with specific risk factors of transmitting blood borne viruses. These include a prison resource and an Indigenous resource.

### **Other Education Resources**

**Handy Hints** offers information on hepatitis, safer sex, sexual health, overdoses and other emergencies, tests and treatments and a directory of state and territory laws and services.

**Hep See** Magazine is a quarterly magazine informing professionals and the public about what's happening in the Education Program.

### **"Dancing in the Dark"**

An AIVL video resource targeting the Indigenous injecting and illicit drug users community

AIVL will not be defining this community. The vision behind this production is to include three separate stories about blood awareness - in a family, in an injecting' community and in a 'gay, sistergirl and transgender' community.

## **Developing Indigenous Branded Condoms**

### **Rachel Tregonning**

Marie Stopes International Australia

---

### **Marie Stopes International - Australia (Providing reproductive health care to women and their families around the world)**

#### **Who we are?**

Australian non-profit organisation.  
Local partners in Asia.  
Marie Stopes International partnership  
-39 countries throughout Africa, Middle East, Latin America and Europe.

#### **What we do?**

Reproductive health care services:

Family planning  
Contraceptive distribution  
Sexually transmitted infection (STI) prevention, diagnosis and treatment  
HIV/AIDS education and prevention  
Safe motherhood  
Male awareness programs  
Mobile outreach service  
Social marketing of contraceptives

### **Indigenous Australia MSIA**

#### **Working with Indigenous communities to improve reproductive health:**

##### ***What now?***

An unmet need.  
Program Support Manager for Indigenous Health

##### ***Reproductive health initiatives***

Partnerships  
- Vital to success  
- Cultural sensitivity  
- Indigenous communities identify, control and develop their own health solutions  
Aboriginal self-determination and community control

### **Condom Social Marketing**

## **Social Marketing of Condoms to reduce the spread of STI/HIV infections in Indigenous communities**

### **Background**

Conditions conducive to rapid, widespread transmission of HIV:

- High rates of STIs
- Low condom use rates
- Highly mobile lifestyles
- Over representation in prisons
- Alcohol and substance abuse problems
- Traditional ceremonial practices

### ***Rationale***

Consistent condom use is the only method that prevents both STI/HIV transmissions.  
However, in many Aboriginal and Torres Strait Islander communities condom use is minimal.

### **PLACE**

#### ***Rationale***

In many of these communities condom availability and accessibility is limited  
Condoms need to be accessible at a place where Aboriginal people gather and at a time they are making a decision about their sexual behavior  
Finding new ways to provide condoms to Aboriginal people will help reach new groups of potential users

### **PRODUCT**

#### ***Rationale***

Condom brands currently available in Australia are targeted towards white Australian's.  
These are not in any way culturally relevant to Aboriginal and Torres Strait Islander people.

Condom attributes need to have greater appeal to Aboriginal and Torres Strait Islander people  
A high demand, 75% survey respondents so far indicated they would be more likely to wear a condom with an Indigenous designed package compared to a standard condom

### **PROMOTION**

#### **Rationale**

Campaigns need to teach people about safe sex via condom promotion.

As pointed out by the WHO, 'Condom promotion results in increased use of condoms as well as a decrease in STI/HIV rates.'

As demonstrated in Thailand, successful condom promotion initiatives increased condom use in some provinces from 30% to 90% and STI rates dropped from 13% to less than 0.5%.

## **Proposed Strategy**

MSIA are seeking to bring their international social marketing expertise to bear in Indigenous communities in Australia.

The social marketing of condoms is a process that adapts proven marketing tactics to raise awareness, change attitudes and change social behavior in order to promote safer sexual practices by increasing condom use.

Once again, as pointed out by the WHO, 'Condom social marketing programmes have succeeded in increasing the use of condoms in many countries.'

Every aspect of this project will be developed in conjunction with ACCHOs and ACCHSs from around the country and Indigenous people within the target groups from the local communities.

It will be culturally relevant and gender sensitive.

## **Objectives**

To improve the reproductive/sexual health of Aboriginal and Torres Strait Islander people by reducing the spread and incidence of STI/HIV infections.

To use social marketing techniques to make an Indigenous branded condom readily available and desirable.

To implement behaviour communications initiatives to increase STI/HIV awareness and make condom use acceptable and habitual.

## **Target Groups**

Aboriginal and Torres Strait Islander people of reproductive age with a particular focus on high-risk groups including:

- o Young people aged between 13-30
- o Homosexual males
- o Intravenous drug users

## **Expected Outcomes**

The development of a culturally relevant Indigenous branded condom brand that greatly appeals to Aboriginal and Torres Strait Islander people, available to communities nationwide

The development and launch of a promotional campaign highlighting the importance of safe sex practices by using condoms helping to prevent the transmission of STI/HIV

The establishment of effective distribution and supply networks to make the Indigenous branded condom easily accessible and available to Aboriginal and Torres Strait Islander people

The distribution of:

- 5,000 condoms to Indigenous people in Mildura within phase/year 1
- 30,000 condoms to Indigenous people in Victoria within phase/year 2
- 400,000 condoms to Indigenous people nationwide within phase/year 3

## **Sharing experiences**

The session at Anwernekenhe III is for non-gay Indigenous, non-Indigenous gay and non-Indigenous non-gay participants

### **Example: Doing sessions on gay men's issues**

Developed the materials as part of the training process  
Meant stepping over organisational boundaries  
Importance of flexibility/opportunism

### **Example: Support Indigenous Social group**

Administer money  
Be part of something without taking it over  
Difficulties with group cohesion - it destroyed itself from within  
Not an Indigenous thing

### **Support versus control**

Hold back expertise because not invited  
The difficulty is empowerment, or providing an enabling environment  
Barriers include personal and community history, and current personal circumstances  
Sometimes the same things work or don't work in different situations, but when they don't work you don't get the chance for critical reflection with the group on what went wrong  
The conduct of research

### **Intimidation/Intimidating situations**

Recruitment - needs flexibility in both time frames and processes  
Recruit the right person, then train them to do the job  
Example was NSW partnership public health training

### **Sensitivities**

finding the right person to talk to

elders  
organisations  
ignorance about community structures can make it hard to manoeuvre (in the way you would with a non-Indigenous community)  
use local workers/connections to talk to the right people, meet the requirements of local protocols  
permission  
sometimes being rigid about structures causes problems - eg working with young people where they have conflicts with elders

### **Time frames**

develop trust  
funding need to be for longer  
staff turnover - problem with long project time lines  
long time to develop foundation networks  
survey with service

### *National focus*

means different approaches with urban, rural and remote communities but need to work through local networks, and with local people  
get introduced  
gender is important, though there is flexibility  
managing and meeting expectations is important - not good to surprise people  
other issues can intervene in relation to gender (for eg young gay men in one place didn't want to be seen by a straight male health worker)

### **Service Delivery**

flexibility (outside of hours, outside of clinic)  
may cause problems over visible "work hours"  
men sometimes need to know women's stuff, and women sometimes need to know men's stuff

### **Shame**

Difficult to understand cross-culturally  
Includes different understandings of the implications of different parts of interaction (such as looking/staring and touch)  
Aboriginal people may not be experienced with dealing with white people  
Shame reactions might include withdrawal or anger

### **Sensitivity to levels of abuse in the community**

make counselling available  
make sure people feel free to leave  
be conscious of and prepared for the emotional content of these issues

### **Partnerships**

need to normalise processes of dialogue with organisational cultures  
include Aboriginal people prior to the development of the process  
the importance of advisory structures, especially being involved from the start  
formal mechanisms sometimes lack the flexibility need to allow partnerships to  
move forward, or get in the way of the work of the partnership

### **Priorities**

National priorities are not necessarily local priorities  
Sexual health vs. artificial limbs (Cape York)  
Heart disease vs. roads (Hunter Valley)

### **Equality**

mutual respect needs to be articulated  
expectations between workers and managers go both ways

### **Interviews**

May be difficult to ask direct questions without giving the person time to think  
Sometimes hypothetical scenarios are a better way to go (not as personal)

# **Bloodborne viruses and injecting drug use among Indigenous Australians: Recent findings from epidemiological surveillance**

National Centre in HIV Epidemiology and Clinical Research  
June 2002

## **Summary**

Diagnoses of HIV infection among Indigenous people have occurred at roughly the same annual rate over the period 1992-2001. In the most recent 5-year period there have been 18 reported diagnoses of HIV in Indigenous people with a history of injecting, compared to 14 in the previous period. There is some indication from CD4 counts that the cases were relatively recently acquired.

Surveillance of HIV and hepatitis C infection among attenders at needle and syringe programs has detected an increasing proportion of Indigenous participants, but no indication of differences in prevalence or trends in prevalence according to Indigenous status.

## **Background**

The injection of illicit drugs has been demonstrated to be strongly associated with the transmission of HIV infection in many countries. In Australia, prevention programs based on the principle of harm minimisation have been successful in maintaining low levels of HIV infection in people who inject illicit drugs. On the other hand, extensive transmission of hepatitis C via injecting continues to occur, largely because prevalence was already well established by the time prevention programs were put in place on a large scale.

Several sources of information have indicated that the prevalence of injecting has increased in Australia over the past decade. Anecdotally, there have been suggestions that injecting among Indigenous people has also become more

frequent, but the extent to which trends have differed from those in the non-Indigenous population is unknown.

An analysis was undertaken of recent surveillance data on HIV and hepatitis C in relation to injecting drug use, in order to determine whether there was any indication of emerging patterns of risk.

### **National HIV Database**

Newly diagnosed HIV is a notifiable condition in all States and Territories. The National HIV Database receives information on diagnoses notified to State/Territory health authorities.

Information on Indigenous status has been collected prospectively for HIV/AIDS cases newly diagnosed from May 1995. For HIV/AIDS diagnoses prior to 1995, available information on Indigenous status was obtained retrospectively through State/Territory health authorities. Information on Indigenous status has been reported from 1 June 1998 for HIV/AIDS cases diagnosed in Victoria, and is not reported for cases diagnosed in the ACT.

The overall *per capita* rate of newly diagnosed HIV infection in Indigenous Australians has been similar to the rate in non-Indigenous Australians (Figure 1). Male homosexual contact has been the largest single exposure group in both populations but females and people who report heterosexual exposure have represented a higher proportion of Indigenous cases.

Although the number of diagnoses of HIV infection in Indigenous people with a history of injecting drug use remains small, there has been an increase in such diagnoses (Figure 2, Table 1). Among cases of HIV infection newly diagnosed in 1997 - 2001, a history of injecting drug use was reported for 23.7% (18/76) of Indigenous cases and for 8.1% (281/3469) of non-Indigenous cases. In 1992 - 1996, 15.4% (14/91) of HIV diagnoses among Indigenous people were attributed to injecting drug use whereas 7.7% (306/3972) of non-Indigenous people reported a history of injecting drug use.

**Table 1: Newly diagnosed HIV infection<sup>1</sup> for which a history of injecting drug use was reported**

Characteristic	1992 - 1996		1997 - 2001	
	Indigenou s	Non- Indigenou s	Indigenou s	Non- Indigenou s
Number	14	306	18	281
% male	100	89.2	72.2	90.7
% male homosexual contact	78.6	53.3	33.3	53.0
Median age	28.5	30	29	31
Median CD4 count	452	440	646	450
Newly acquired (%)	5 (35.7)	57 (18.6)	4 (22.2)	72 (25.6)

1. Information on Indigenous status was not available from the ACT at 31 March 2002. Information on Indigenous status was available from VIC from 1 June 1998.

**HIV and hepatitis C prevalence among needle and syringe program (NSP) survey respondents**

Tests for HIV and hepatitis C antibody were conducted among injecting drug users (IDUs) in the National NSP surveys (1995-2001). In these annually repeated cross-sectional surveys, all clients attending selected NSPs during one week in October were asked to complete a brief questionnaire and provide a finger-prick blood sample. The response rate was around 50% each year.

The proportion of respondents describing themselves as Indigenous increased from 1995 (5%) to 2001 (8%, Table 2).

**Table 2: Number and percentage of respondents in NSP survey by Indigenous status, 1995-2001**

Year	Number of sites	Number reporting Indigenous origin (%)	Number reporting non-Indigenous origin (%)	Number with Indigenous status not reported (%)
1995	21	52 (5%)	987 (92%)	33 (3%)
1996	20	66 (4%)	1333 (89%)	98 (7%)
1997	24	101 (5%)	1844 (93%)	33 (2%)
1998	32	167 (6%)	2442 (92%)	56 (2%)
1999	34	182 (7%)	2237 (90%)	84 (3%)
2000	35	233 (9%)	2391 (89%)	70 (2%)
2001	38	188 (8%)	2196 (89%)	70 (3%)

**HIV prevalence**

HIV prevalence decreased from 4.3% (1995) to 1.1% (2001) among Indigenous participants and from 2.1% (1995) to 0.9% (2001) among non-Indigenous respondents. In each year HIV prevalence was similar among Indigenous and non-Indigenous respondents (Table 3).

**Table 3: HIV prevalence by Indigenous status, 1995-2001**

Year	Indigenous		Non-Indigenous		p
	Number tested	Number with HIV (%)	Number tested	Number with HIV (%)	

1995	47	2 (4.3%)	927	19 (2.1%)	0.3
1996	64	3 (4.7%)	1322	22 (1.7%)	0.08
1997	93	2 (2.1%)	1690	25 (1.5%)	0.6
1998	145	2 (1.4%)	2235	18 (0.8%)	0.5
1999	175	4 (2.3%)	2129	30 (1.4%)	0.4
2000	225	4 (1.8%)	2241	18 (0.8%)	0.1
2001	177	2 (1.1%)	2100	19 (0.9%)	0.8

Most jurisdictions had at least one Indigenous respondent with HIV infection in the survey. HIV prevalence was higher among male than female respondents and among male respondents reporting bisexual or homosexual identity than males reporting heterosexual identity (Table 4).

**Table 4: HIV prevalence among Indigenous NSP survey respondents by sexual identity and sex, 1995-2001**

Year / Sexual identity	Males		Females	
	Number tested	Number with HIV (%)	Number tested	Number with HIV (%)
<b>1995-96</b>				
Heterosexual	55	2 (3.6%)	29	1 (3.4%)
Bi/homosexual	10	2 (20.0%)	10	0 (0.0%)
Total*	68	4 (5.9%)	42	1 (2.4%)
<i>P</i>		0.05		0.5
<b>1997-98</b>				
Heterosexual	115	0 (3.6%)	65	1 (1.5%)
Bi/homosexual	15	3 (20.0%)	23	0 (0.0%)
Total*	144	3 (2.1%)	93	1 (1.1%)
<i>P</i>		<0.001		0.6
<b>1999-00</b>				
Heterosexual	180	5 (2.8%)	89	1 (1.1%)
Bi/homosexual	25	2 (8.0%)	62	0 (0.0%)
Total*	227	7 (3.1%)	169	1 (0.6%)
<i>P</i>		0.2		0.4
<b>2001**</b>				
Heterosexual	75	1 (1.3%)	42	0 (0.0%)
Bi/homosexual	16	1 (6.3%)	22	0 (0.0%)
Total*	102	2 (2.0%)	71	0 (0.0%)
<i>P</i>		0.2		-

\* Totals include respondents who did not report sexual identity.

\*\* In 2001, an additional 6 male respondents had unconfirmed reactive ELISA tests, of whom 3 self-reported HIV infection (1 reported homosexual and 1 heterosexual identity - 1 sexual identity not reported) and 3 self-reported no HIV infection (1 reported bisexual and 2 heterosexual identity).

### Hepatitis C prevalence

Similar hepatitis C prevalence was found among Indigenous and non-Indigenous respondents in all years except 1999 (Table 5). In 1999, hepatitis C prevalence was significantly higher among Indigenous compared to non-Indigenous respondents (68% vs. 49%,  $p < 0.001$ ).

**Table 4: Hepatitis C prevalence by Indigenous status, 1995-2001**

Year	Indigenous		Non-Indigenous		p
	Number tested	Number with hepatitis C (%)	Number tested	Number with hepatitis C (%)	
1995	47	34 (72%)	902	564 (63%)	0.2
1996	66	37 (56%)	1298	656 (51%)	0.4
1997	93	50 (54%)	1693	851 (50%)	0.5
1998	145	77 (53%)	2238	1093 (49%)	0.3
1999	174	119 (68%)	2126	1038 (49%)	<0.001
2000	226	118 (52%)	2251	1213 (54%)	0.6
2001	183	112 (61%)	2128	1228 (58%)	0.4

Hepatitis C prevalence was also higher among Indigenous than non-Indigenous respondents reporting less than three years of drug injection in 1998/99 (35% vs. 17%,  $p = 0.002$ ; Table 6). Hepatitis C prevalence among Indigenous respondents reporting less than three years of injection remained high (30%) in 2000/01. Hepatitis C prevalence increased significantly from 1998/99 to 2000/01 among non-Indigenous respondents reporting less than three years of injection (17% to 26%,  $p < 0.001$ ).

**Table 5: Hepatitis C prevalence among respondents reporting less than three years of drug injection by Indigenous status, 1995-2001**

Year	Indigenous		Non-Indigenous		P value
	Number tested	Number with hepatitis C (%)	Number tested	Number with hepatitis C (%)	
1995-97	20	1 (5%)	652	94 (14%)	0.2
1998-99	48	17 (35%)	781	135 (17%)	0.002
2000-01	46	14 (30%)	557	148 (27%)	0.6

Among non-Indigenous respondents reporting less than three years of drug injection, there was a trend of increasing hepatitis C prevalence from 1996 to 2001 (Figure 3). Among Indigenous respondents hepatitis C prevalence increased to 35% (1998/99) from 5% in 1995/97 ( $p < 0.01$ ).

## Discussion

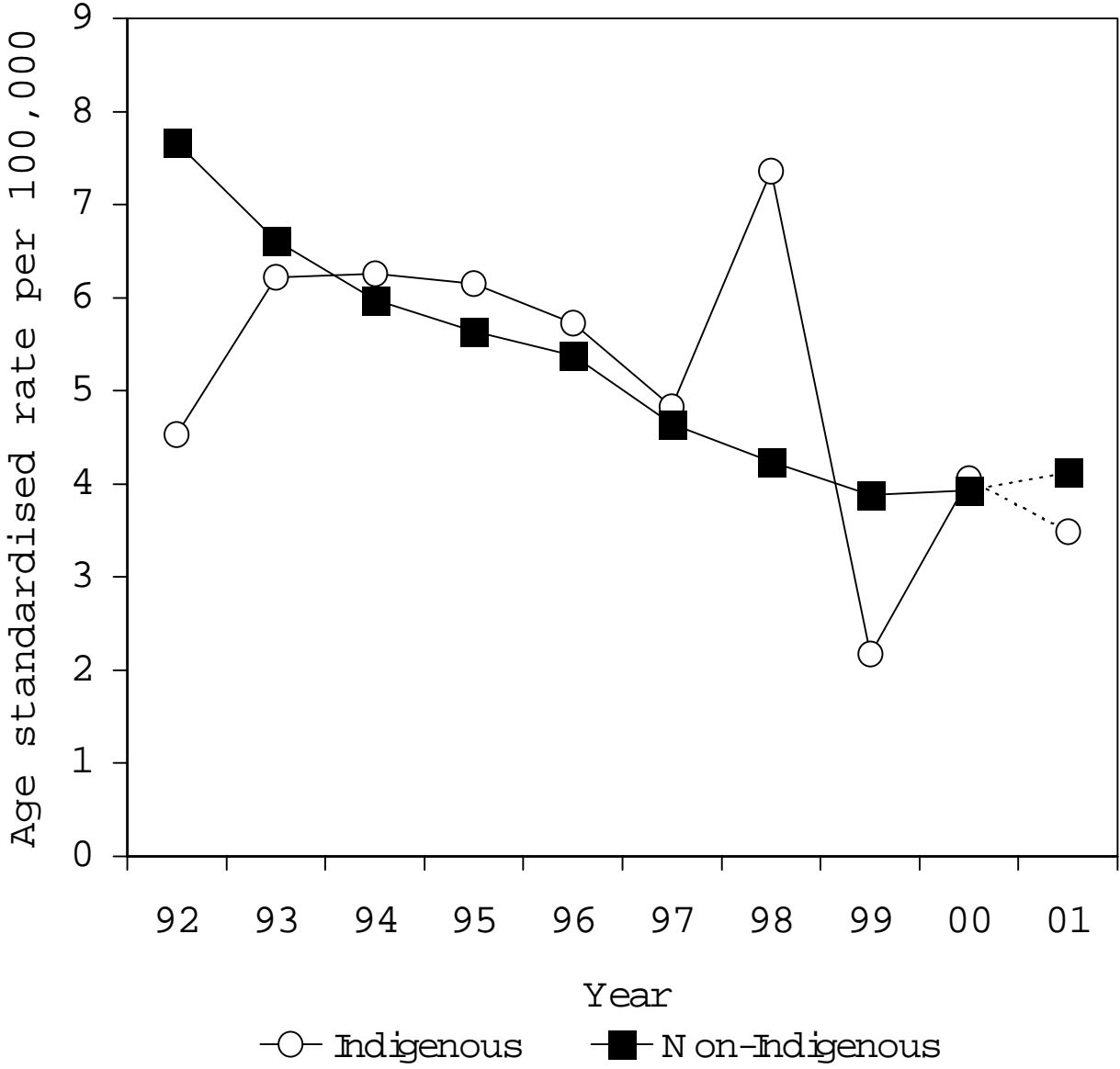
Rates of hepatitis C infection among Indigenous people attending needle and syringe programs, in particular among those with a relatively short duration of injecting, indicate ongoing injecting risk behaviour. In contrast, prevalence of HIV infection monitored through needle and syringe program surveys remains low for both Indigenous and non-Indigenous injecting drug users. Although numbers of HIV diagnoses attributed to injecting drug use in Australia remain small, there has been some increase in Indigenous diagnoses in more recent years. However, trends in Indigenous HIV diagnoses need to be interpreted in light of limitations in national HIV surveillance data. National reporting of Indigenous status at HIV diagnosis was not established until May 1995. In Victoria, reporting of Indigenous status at HIV diagnosis did not commence until June 1998. Indigenous status may be under ascertained, and underreported, especially prior to 1995, and the reporting of Indigenous status at HIV diagnosis may not be standardised across State/Territory health jurisdictions. HIV

exposure may also be limited by incomplete ascertainment of exposures other than injecting drug use. For example, a history of male homosexual contact may be underreported among males and a history of heterosexual contact with an injecting partner with HIV infection may be underreported among women with a limited history of injecting drug use.

Consideration of surveillance limitations is also required in interpretation of the low HIV prevalence among Indigenous injecting drug users in the needle and syringe program survey. These limitations include possible antibody testing insensitivity due to the use of dried blood spot, a participation rate of approximately 50% of clients during the survey period, and possible non-generalisability. Many injecting drug users do not attend needle and syringe program sites, and these people may be either at decreased or increased risk of HIV and hepatitis C infection. Injecting drug users with no access to needle and syringe programs would not be included in the survey and may be at considerably greater risk of blood-borne viral infection.

Close monitoring of trends in HIV and hepatitis C prevalence and notifications among Indigenous injecting drug users is required. In addition, an assessment of access to harm-reduction strategies among Indigenous populations would provide important information regarding service needs and assist in assessment of the generalisability of findings from the needle and syringe program survey. Expansion of the survey to include sites with a relatively high Indigenous client population would also provide important additional surveillance information.

Figure 1: Newly diagnosed HIV infection, 1992 - 2001, by Indigenous status and year



**Figure 2: Newly diagnosed HIV infection, 1992 – 2001, by Indigenous status, exposure category and year**

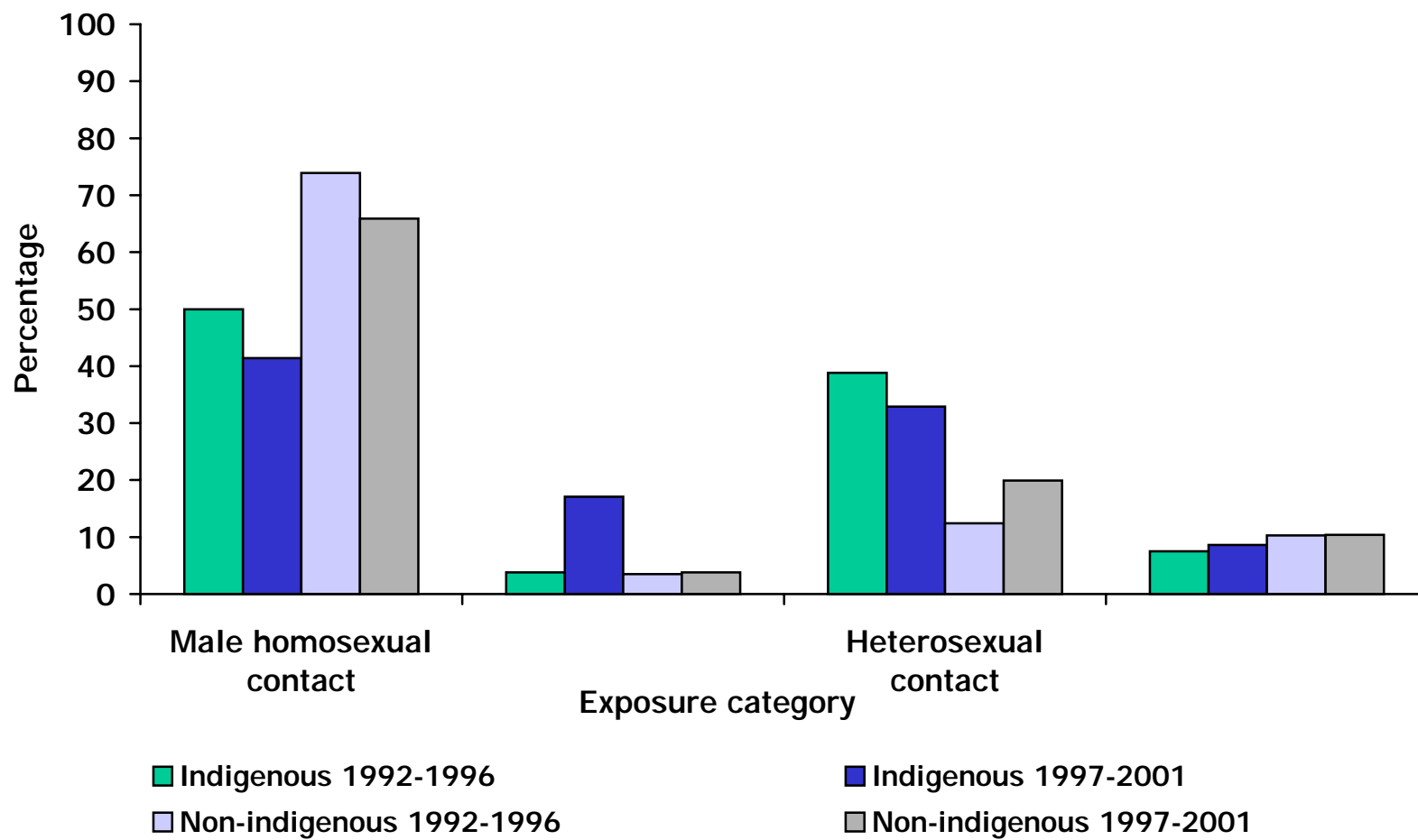
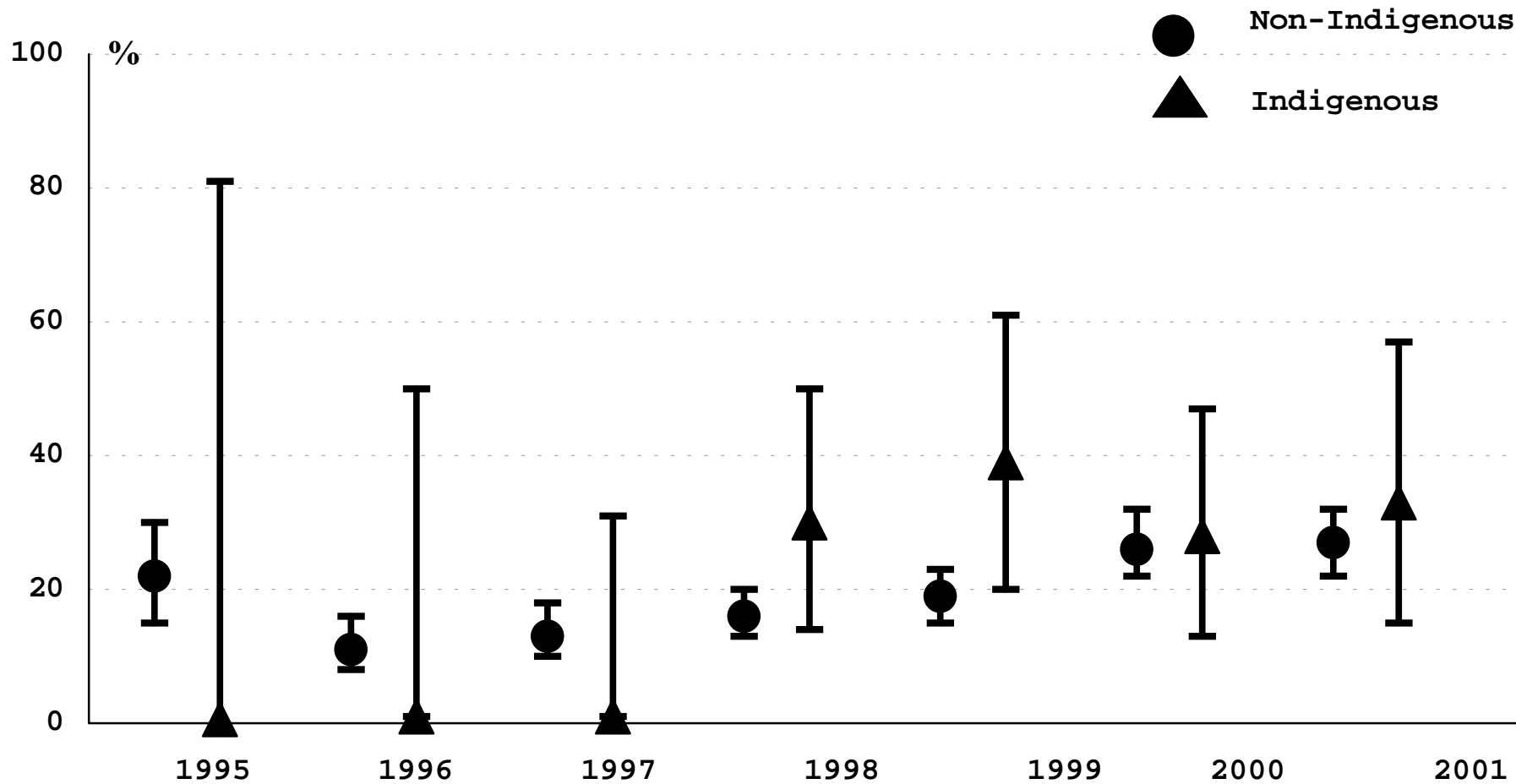


Figure 3: Hepatitis C prevalence among respondents reporting less than three years of drug injection by Indigenous status, 1995-2001



## HIV Futures II

### Aboriginal and Torres Strait Islander People Living with HIV

Jon Willis, Karalyn McDonald, Mark Saunders & Jeffrey Grierson

---

#### *About the Study*

- 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
- 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.

#### *Some Warnings*

- We can't draw general conclusions about the experience of all Aboriginal and Torres Strait Islander people living with HIV
- The total number of Aboriginal and Torres Strait Islander responses to the survey is very small
- Not designed to explore issues about living with HIV that are distinctive for Aboriginal and Torres Strait Islander people
- Did not specifically target Indigenous Australians

#### *The people who completed the survey*

- Of the 924 PLWHA who completed the survey, 23 identified as Aboriginal or Torres Strait Islander people.
- Around 15% of the 155 Aboriginal or Torres Strait Islander people whose HIV infection has been notified HIV in Australia to the end of 2000
- 18 men, 4 women, 1 unidentified
- 12 gay or lesbian, 5 straight and 6 bisexual
- Ages ranged from 30 to 59, with an average of around 38 years

#### **How infected:**

- Ten of the men cited homosexual contact
- Three men cited homosexual contact and injecting drug use
- Seven people including the four women respondents cited heterosexual contact
- Three people did not indicate
- 14 are from NSW, 4 from Qld, 3 from Vic, 1 from SA, and 1 from WA
- 8 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

*Health and HIV*

- Two thirds (15) feel good about their general health
- most are actively doing things to improve their health
  - a good diet (18)
  - relaxation (17)
  - taking pills on time (16)
  - exercise (16)
  - getting adequate sleep (13)
- 4 diagnosed with an AIDS defining illness at some point
- 4 reported having experienced an illness or condition related to HIV
  - oral hairy leukoplakia, chronic diarrhoea, wasting/weight loss, candida, vaginal thrush and cervical dysplasia (one case of each)
- More than half the respondents also reported disorders relating to HIV medications
  - lipodystrophy (3), weight loss (12), sleep disorder (15), and memory loss or confusion (12)
- 5 respondents also experienced health conditions other than HIV/AIDS
- More than two thirds (16) 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
- Most were actively monitoring their health through regular CD4/T-cell tests and viral load tests – 14 gave their most recent results

**Table 1** **Results of serological testing**

<i><b>Description</b></i>	<i><b>Result</b></i>	<i><b>Number</b></i>
<b>CD4/T-cell count</b>	<b>cells/ml blood</b>	little or no immune
damage	over 500	13
moderate immune damage	250 – 500	5
severe immune damage	below 250	2
<b>Viral load</b>	<b>copies/ml blood</b>	
below detectable level	below 200 / 500	13
low	500 - 10,000	0
moderate	10,000 - 50,000	0
high	over 50,000	1

- For their main general medical treatment, they identified their HIV specialist (11) followed by their HIV GP (6) or their generalist GP (4)

### *Mental Health and Support*

- ***In the last six months...***
  - half (12) respondents had been taking medicine for anxiety, compared to 29.0% of the rest of the sample.
  - 3 respondents reported taking anti-psychotic medication
  - 1 respondent reported taking medication for depression.
- Just over half of the respondents were using the counselling services available at HIV/AIDS organisations and other agencies.
- Most respondents have reasonable levels of support from their social networks
- However 4 respondents didn't get 'a lot' of support from anyone.
- The richest sources of support
  - partners/spouses (13)
  - close friends (10)
  - parents (7)
  - HIV positive friends (8)
  - pets (10)

### *HIV Treatments*

- (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.

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

	<b>Aboriginal &amp; Torres Strait Islander respondents</b>	<b>Non-Aboriginal &amp; Torres Strait Islander respondents</b>
<b>Using antiretroviral drugs</b>	(18) 76.0%	73.4%
<b>Using OI prophylaxis</b>	(6) 26.9%	32.4%
<b>Using alternative therapies</b>	(11) 48.8%	55.1%

**Sex and relationships**

<b>Sexual relationships</b>	<b>Aboriginal and Torres Strait Islander respondents %(n)</b>	<b>Non Aboriginal and Torres Strait Islander respondents %</b>
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
casual sex	Regular relationship	8.7 (2)      18.2plus
Regular with two or more people	3.6 (1)	2.4

- More than half the respondents said they were currently in a regular relationship (14).
- Almost two thirds of those in a regular relationship have a spouse or partner also living with HIV/AIDS (8).
- All 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.
- Most Aboriginal and Torres Strait Islander respondents were afraid of infecting their current or future partners (19)
- 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 respondents reported that HIV had a negative effect on their sexual pleasure

*Recreational Drug Use*

- Alcohol is the most commonly used recreational drug (17)

- half (12) smoke cigarettes.
- 3 reported using prescribed methadone.
- 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 the respondents reported using other recreational drugs:
  - amyl (6)
  - heroin (injected – 6)
  - LSD (5)
  - ecstasy (4)
  - cocaine (not injected – 4; injected – 4)
  - speed (not injected – 4; injected – 2)
  - Steroids (1)
  - Ketamine (1)

### *Injecting*

- More than half of the respondents said they had never injected illegal drugs and of those who had (10)
- 2 had done so over a year ago.
- Of the 8 respondents who had injected drugs in the last 12 months, only one person had shared needles in the past 12 months (using risk reduction strategies including bleaching the needle and using the needle last)

### *Discrimination*

- Almost half of the respondents (10) felt they had received less favourable treatment than other people at medical services because of their HIV
- 5 have experienced less favourable treatment than other people at work as a result of having HIV/AIDS.
- 4 respondents said they had changed their accommodation as a result of having HIV/AIDS in order to avoid harassment.
- The majority of 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) respondents had some contact with 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)
  - financial assistance and advice (5)
- Most respondents spent a little time (8), some time (7) or a lot of time (6) with other PLWHA.
- More than three-quarters (18) of 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.

### *Information*

- Aboriginal and Torres Strait Islander respondents nominated different people as important sources of information
- For information about treatments for HIV/AIDS, they 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, they 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
- Areas where there was a lack of information
  - the management of side effects from ARV (12)
  - financial planning (9)
  - taking a break from antiretroviral therapy (8)
  - interactions between ARV and other medications (8)
  - recreational drug use (8)
  - using ARV drugs (6)
  - changing ARV drugs (6)
  - legal issues (6)

### *Employment*

- Almost two thirds (14) of 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.
- Around one quarter (6) of respondents are currently in paid employment
- 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
- 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 respondents are living below the poverty line (about the same as other PLWHA)
- More than half of respondents (13) are primarily dependent on a government benefit or pension
- 8 people said their main source of income was a salary
- 1 person said their main source of income was superannuation/savings/annuity.

### *Difficulties with meeting the cost of living*

- going out (17)

- utilities (16)
- transport (15)
- travel/holidays (14)
- clothing (13)
- entertainment (13)
- Food (12)
- medical services (12)
  
- rent/mortgage/
- housing costs (12)
- complementary therapies (10)
- co-payments for medication for HIV/AIDS (9)
- other prescribed medication (8)

*Other Indigenous work at ARCSHS*

- Projects with an ATSI focus
  - Koori Men's Health
  - VACCHO Well Person's Health Check
  - Prioritising the Research Agenda in Indigenous Sexual Health
  - Mapping Indigenous Risk Workshop
  - Gay men, homophobia & sexual violence
  - Indigenous Futures: sex, drugs & medication
  - TriState STD/HIV program evaluation
  
- Projects with ATSI cohorts
  - Futures II and III
  - Women & Hep C
  
- Projected Projects
  - Assessing Indigenous Sexual Risk
  - Learning to inject "inside"

The Living with HIV Program is a part of the research program at the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University, Melbourne, Australia.

ARCSHS is funded by the Victorian Health Promotion Foundation to undertake a program of social research into social, psychological and cultural aspects of human sexuality and sexual health and is affiliated with The University of Melbourne.

ARCSHS is funded by the Australian Department of Health & Aged Care as a Collaborating Centre to The National Centre in HIV Social Research.