

The background is a large, intricate Aboriginal dot painting. It features a central circular motif surrounded by various scenes and symbols. The scenes include a group of people gathered outdoors, a person sitting at a table, a group of people sitting on a bench, and a person sitting at a desk. The symbols include a red parrot, a white cockatoo, a blue and white bird, and a white bird. The painting is composed of many small dots in various colors, creating a rich, textured effect. The overall theme is community and cultural heritage.

# HIV

## AUSTRALIA

Volume 13 • Number 3

**Fire in the belly: the call to action on HIV  
from Aboriginal and Torres Strait  
Islander communities**



**Editors** Finn O'Keefe and Linda Forbes

**Guest Editors** James Ward and Michael Costello-Czok

**Treatments Editor** Jason Appleby

## Editorial

**It is with great pleasure that we launch the second special edition of *HIV Australia* dedicated to Aboriginal and Torres Strait Islander health issues. This edition has been produced to coincide with the 2015 Aboriginal and Torres Strait Islander HIV Awareness Week (ATSIHAW) and to commemorate the 21st anniversary of the Anwernekenhe movement, fighting to protect the rights of Aboriginal and Torres Strait Islander people affected by HIV. After the previous special edition's success in 2013, this edition comes at a timely point in our contemporary histories for Aboriginal and Torres Strait Islander peoples and HIV.**

The Aboriginal and Torres Strait Islander-led response to HIV is at a crossroads; we have the tools to address HIV, but how do we ensure that the latest HIV prevention methods and knowledge is reaching our communities? Articles in this edition showcase current community-driven programs across the country and highlight actions required to stimulate political action and maintain vigilance and awareness about HIV among Aboriginal and Torres Strait Islander communities. What actions do we need to take now to safeguard the health of Aboriginal and Torres Strait Islander communities into the future?

Now more than ever, we need to galvanise our efforts in HIV health promotion and prevention – focusing on the new tools we have in the biomedical prevention front, as well as the new information that arises from research – to be able to address HIV appropriately in our communities.

The articles which follow illustrate the great amount of work happening across Australia to address HIV among our peoples, ranging from the HIV Free Generation campaign run by the Aboriginal Health and Medical Research Council in NSW, to the work being done by the state and territory AIDS Councils and efforts by national community HIV organisations and governments to end HIV.

While these are all good efforts, there are some significant threats to maintaining low HIV rates in Aboriginal and Torres Strait Islander communities, including: very high rates of sexually transmissible infections (STIs) in many Aboriginal and Torres Strait Islander communities; an ever impending threat that HIV will rapidly escalate in our populations who inject drugs; and the threat that HIV will make its way from Papua New Guinea and other neighbouring countries into our communities.

This edition gives us an opportunity to take stock of what is occurring across the country and reflect on where we've been and where we need to go in the future to prevent HIV from being just another health condition in our communities. What we require is a way to track our progress, to challenge ourselves, to mobilise our communities and for us all to be motivated about our own roles in this story.

We hope this special issue of *HIV Australia* motivates you to play your part in preventing HIV from taking hold in our communities. Finally, in closing, this edition would have not been possible without the exceptional efforts of Linda and Finn at AFAO for bringing this all together. Enjoy the read and keep up the great work!

Sincerely, James Ward and Michael Costello-Czok



**James Ward** is an Indigenous health researcher with more than 17 years' experience. He is a descendent of the Pitjantjatjara and Nurrunga clans of central and South Australia.



**Michael Costello-Czok** has over 20 years' experience working in the community response to HIV. He is Central Arrernte of the Arrernte Nation.

**Aboriginal and Torres Strait Islander people should be aware that this magazine may contain images or names of people who have passed away.**

The Australian Federation of AIDS Organisations (AFAO), the Anwernekenhe National HIV Alliance (ANA) and the editors of this edition of *HIV Australia* acknowledge the traditional owners of the lands we operate on across Australia, and pay respect to Indigenous Elders past and present.

This edition is dedicated to ongoing survival of those living with HIV and to Aboriginal and Torres Strait Islander people whom we have lost to HIV/AIDS. Without the determination and tenacity of these pioneers, we wouldn't be where we are today.

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**AFAO is the national federation for the HIV community response, providing leadership, coordination and support to the Australian policy, advocacy and health promotion response to HIV/AIDS. Internationally, AFAO contributes to the development of effective policy and programmatic responses to HIV/AIDS at the global level, particularly in the Asia-Pacific region.**

AFAO's aims are to:

- Advocate on behalf of its members at the federal level, thereby providing the HIV community with a national voice;
- Stop the transmission of HIV by educating the community about HIV/AIDS, especially those whose behaviour may place them at high risk;
- Assist its members to provide material, emotional and social support to people living with HIV;
- Develop and formulate policy on HIV issues;
- Collect and disseminate information for its members;
- Represent its members at national and international forums; and
- Promote medical, scientific and social research into HIV and its effects.

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HIV Australia welcomes submissions from interested authors.  
To submit an article or report for consideration, email [editor@afao.org.au](mailto:editor@afao.org.au)

# U And Me Can Stop HIV: Aboriginal and Torres Strait Islander HIV Awareness Week 2015

By James Ward

Aboriginal and Torres Strait Islander HIV Awareness Week (ATSIHAW) is an annual program of events that seeks to raise awareness about the impact of HIV among Aboriginal and Torres Strait Islander people. Although the inaugural event was only held twelve months ago, it is already well recognised as key event for raising awareness and mobilising action to address HIV among Aboriginal and Torres Strait Islander communities. This year, after much preparation, the 2015 ATSIHAW program is a bigger affair than 2014, with numerous events organised nationally. This is vital, as ATSIHAW 2015 occurs at a time when raising awareness about HIV among our communities is more important than ever. HIV diagnoses among the Aboriginal and Torres Strait Islander population is increasing, yet for many years now there has been little or no investment by governments targeted at enhancing our communities' knowledge and awareness of HIV. While the number of annual HIV diagnoses for Aboriginal and Torres Strait Islander people is fairly low at present (around 30 new diagnoses per year), in 2014 the notification rate of newly diagnosed HIV infection was 1.6 times higher for the Aboriginal and Torres Strait Islander population compared to the non Indigenous population (5.9 vs 3.7 per 100,000 in 2014).

The potential exists for HIV to escalate rapidly in the Aboriginal and Torres Strait Islander population – as has been the experience in other Indigenous populations globally. This potential is due to three main issues:

- very high rates of other sexually transmissible infections (STIs) exist in many communities, and the presence of these increases the chances that HIV can be transmitted
- increasing rates of injecting drug use – including increasing rates of methamphetamine (ice) use in Aboriginal communities, and
- the close proximity of Papua New Guinea (PNG) to the Torres Strait Islands, and the mobility and interaction of PNG nationals and Torres Strait Islanders. PNG has the highest recorded rates of HIV in the Asia-Pacific region.

In the five year period 2010–2014, when comparing rates of new HIV infection among the Aboriginal and Torres Strait Islander population with the non-Indigenous Australian born population, a higher proportion of notifications were attributed to injecting drug use (16% vs 3%); heterosexual sex (20% vs 13%); and 22% vs 5% of new HIV diagnoses were among females.

Based on CD4+ cell counts at diagnosis, in 2014 a third (30%) of the new HIV diagnoses among the Aboriginal and Torres Strait Islander population were determined to be late.

## ATSIHAW events

The 2015 ATSIHAW was launched at Wuchopperen Aboriginal Health Service in Cairns on the 30 November. Speakers included Assoc Professor James Ward, SAHMRI (South Australian Health and Medical Research Institute), Dr Mark Wenitong, Apunipima Cape York Aboriginal Health Council, HIV-positive speakers, and youth and elders from the Cairns region and community.

The launch was followed by a training day on Tuesday the 1 December for health service staff working in the Cairns region, to learn about updates on HIV diagnosis, risk factors, prevention strategies, treatment updates, care and management of people living with HIV and outbreak management – including privacy confidentiality stigma and discrimination.

On 2–3 December, ATSIHAW, in partnership with the HIV Foundation Queensland, ASHM (Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine) and the National Aboriginal Community Controlled Health Organisation, hosted a high level summit in Brisbane to discuss strategies and actions for moving forward an agenda that is urgently required. The Summit, opened by the Queensland Health Minister, the Hon Cameron Dick MP, was held in recognition of the need to urgently address the fact that STIs and blood borne viruses are part of our communities' overwhelming burden of disease, particularly:

- for remote communities – STIs (chlamydia, gonorrhoea, syphilis and trichomonas), as well as hepatitis B

- for urban and regional areas – hepatitis C and chlamydia
- emerging HIV transmission risks from drugs such as methamphetamines ('ice') – both due to unsafe injecting and condomless sex.

During ATSIHAW, community events were held across Australia at over 30 Aboriginal Community Controlled Health Services in most jurisdictions and at other HIV organisations such as AIDS Councils, aimed at raising awareness of HIV in our communities. Our Facebook page (<https://www.facebook.com/ATSIHAW>) lists all the events and happenings for Aboriginal and Torres Strait Islander HIV Awareness Week 2015.

ATSIHAW also recruited high profile Ambassadors to help spread the word about HIV in our communities and the roles all individuals can play in stopping HIV. Our ATSIHAW Ambassadors include Prof Pat Anderson AM, Prof Kerry Arabena, Dr Marlene Kong, and Mr Dion Tatow, to name a few. Profiles of some of our ATSIHAW Ambassadors accompany this article.

SAHMRI is hosting a national exhibition of artworks by Aboriginal and Torres Strait artists from all of Australia's states and territories and the Torres Strait Islands. The *HANDPRINTS* exhibition tells stories of how HIV can affect our peoples, our families and our communities. This exhibition is about our Dreaming – our creation, our land, our people, our totems, our past and future.

You can read more about the planning, rationale and success of some of the ATSIHAW events throughout the pages of this edition of *HIV Australia*, as well as discussion about key programs and research projects being led by Aboriginal and Torres Strait Islander people around the country, to stop the spread of HIV and STIs.

**Associate Professor James Ward is Head, Infectious Diseases Research Aboriginal and Torres Strait Islander Health at South Australian Health and Medical Research Institute (SAHMRI) and a guest editor of *HIV Australia*.**





## ATSIHAW National Ambassador

### Steven Oliver

Steven is a descendant of the Kukuyalanji, Waanyi, Gangalidda, Woppaburra, Bundjalung and Biripi peoples. He studied at the Aboriginal Music Theatre Training Program in Perth, and was subsequently accepted into the Music Theatre Programme at the West Australian Academy of Performing Arts (WAAPA).



Upon his return to Queensland, he took on the role of Assistant Artistic Director with the Aboriginal Centre for the Performing Arts in Brisbane. He has worked with companies such as Yirra Yaakin Noongar Theatre, Kooemba Jdarra Theatre, La Boite Theatre, Jute Theatre, Kite Theatre and the Queensland Arts Council.

His musical, *Black Queen Black King*, was shown as part of Queensland Theatre Company's Creative Development Series and his play, *Proper Solid*, produced by Jute Theatre in 2014, will tour Queensland in 2016. He is also a writer, poet, actor and associate producer for ABC's Logie nominated sketch show *Black Comedy*.

'I'm doing this because I want to help fight and breakdown the stigma associated with HIV and those living with it.'

## ATSIHAW Ambassador

### Ms Pat Anderson, AO

Pat is an Alywarre woman known nationally and internationally as a powerful advocate for Aboriginal and Torres Strait Islander people. She has extensive experience in Aboriginal health and advocacy and currently serves as the Chairperson of the Lowitja Institute. In 2014, Ms Anderson was appointed Officer of the Order of Australia for distinguished service to Australia's First Peoples.



'In the mid-1990s, I was part of the campaign to establish the national Aboriginal and Torres Strait Islander HIV/AIDS strategy. A lot has changed in the past 10 years, so get tested if you are worried because there are great treatments available. Let's keep on talking about HIV, stay safe and look after each other.'

## ATSIHAW Ambassador

### Amanda Sibasado

Amanda is a 28 year old Bard and Wardandi woman. She is passionate about holistic sexual health for our mob. She believes everyone has the right to safe, consensual, pleasurable sexual experiences. She is currently the Sexual Health Coordinator at Kimberley Aboriginal Medical Services.



'HIV is a preventable disease. Let's keep our communities safe – use condoms and get tested for HIV regularly.'

## ATSIHAW Ambassador

### Marlene Kong, Program Head – Aboriginal and Torres Strait Islander Health Program, Kirby Institute, University of NSW

'As a Worimi woman, I am passionate about improving the health of Australian Aboriginal and Torres Strait Islander people. It cannot be done without our people involved in every aspect of health care, from the ground up to the Prime Minister of Australia, acting in good faith. Australia has a long way to go in bridging the big cultural gap that continues to exist in our practices today; HIV awareness and rates among our people being one of the growing and persistent health disparities. I call upon the leaders of our nation – especially those working in HIV medicine – to lead by example in addressing this important gap.'



## ATSIHAW Ambassador

### Mario Assan, Senior Public Health Officer – Indigenous Sexual Health, Thursday Island Primary Health Care Centre

'My name is Mario Assan, I am a Torres Strait Islander with family connections to Badu Island. HIV prevention is important, particularly in Indigenous communities, to ensure the future of our communities is healthy and prosperous. People living with HIV should be supported, loved and accepted by our communities so that they feel that they are still part of our community. Discrimination should not be tolerated by anyone; we are all one people, regardless of race, religion or sexuality.'



It is important for the conversation about HIV and sexual health to be regularly highlighted on an everyday basis. HIV awareness should be discussed every day – not only on World AIDS Day. Highlighting good news stories in our communities is an important way to promote the fact that people can live healthy lives if they access treatment quickly and live normal lives with adequate support and medication.'

## ATSIHAW Ambassador

### Bobby Maher

Bobby is a Yamatji woman with ancestral ties to the Pilbara and Kimberley, born and raised on Njaki Njaki country in the South West of Western Australia (WA). Bobby is passionate about promoting positive health messages in sexual health and respectful relationships through a human rights lens. Bobby is currently working for Sexual and Reproductive Health WA as an Educator/Project Officer with the Pilbara Project.



'It is important for our mob and all communities to have positive and clear messaging about HIV. If HIV gets into our communities it might be a real disaster for families. Understanding about preventing and managing HIV is really important. HIV is not a death sentence now. With good care, people with HIV can live a full and healthy life. Barriers such as discrimination and stigma can attack people's self-esteem and prevents them from accessing health services. We need all our communities and services to understand this and to be the best that they can.'

## ATSIHAW Ambassador

### Dion Tatow

Dion is Aboriginal (Iman and Wadja) and South Sea Islander (Ambrym Island, Vanuatu). Dion is currently the Senior Policy Officer – Mental Health with the Queensland Aboriginal and Islander Health Council (QAIHC). Dion has a Bachelor of Business degree and a Graduate Certificate in Health Service Management.



Dion has worked in Aboriginal and Torres Strait Islander health for 20 years – for both the Commonwealth (OATSIH) and state governments (Queensland Health) – and for the past nine years at QAIHC. His roles have focused on program development, implementation and policy development and evaluation, with a particular focus on social and emotional well being/mental health and sexual health/blood borne viruses in Aboriginal and Torres Strait Islander communities.

Dion has been involved with Aboriginal and Torres Strait Islander community-based organisations since the early 1980s as an elected committee member.

'Increasing rates of HIV infection amongst our population are concerning. We all need to increase our knowledge of HIV, protect ourselves against HIV infection and support those members of our communities living with HIV.'

## ATSIHAW Ambassador

### Arone Meeks

Arone Meeks is a Kuku Midigi man, currently residing in Cairns. He grew up near El Arish, in far north Queensland, although his country is the area around Laura, Cape York. He completed a Bachelor of Visual Arts at the City Art Institute in Sydney in 1984 and has forged an impressive national and international career since.



A former member of the Boomalli urban Aboriginal artist's co-operative, he won an Australia Council fellowship to study in Paris in 1989 and went on to exhibit throughout Europe and North and South America. His work appears in many national and international collections, both public and private. In Australia, he is represented in many public collections, including the National Gallery of Australia and the Queensland Art Gallery. His pieces are also represented internationally in collections in Canada, the United States, France and Japan.

'HIV is everybody's business. Let's not make it part of our story – have an STI test.'

## ATSIHAW Ambassador

### Professor Kerry Arabena

Prof Arabena is a Torres Strait Islander woman and current Chair for Indigenous Health and Head of the Indigenous Health Equity Unit at the University of Melbourne.

'We all need to do our bit to prevent HIV from escalating in our communities. I know we have been talking about it for a long time, but now more than ever we need to look after ourselves and each other. We can do this by getting tested.'



# Remembering, Recognising and Responding: 21 years of the Anwernekenhe Aboriginal and Torres Strait Islander response to HIV

By Michael Costello-Czok and Neville Fazulla

## Introduction

*'We recognise HIV/AIDS as a major health care threat to Aboriginal and Torres Strait Islander people. We also recognise and acknowledge Aboriginal and Torres Strait Islander Australians are dying alone and in shame of AIDS. This must stop.'*<sup>1</sup>

This statement, made in 1994 by Aboriginal and Torres Strait Islander gay men and sistersgirls attending Anwernekenhe 1 – First National Aboriginal and Torres Strait Islander Gay Men and Transgender Sexual Health Conference, mobilised a community response to HIV and set the foundations of the Anwernekenhe movement.

The Anwernekenhe 1 gathering, held at Hamilton Downs on Arrernte Country, just outside of Alice Springs, took place over four days from October 31 to November 4, 1994. The conference brought together 73 participants from across Australia who together formulated 45 recommendations (refined down from over 100 recommendations from participants), as an urgent call to action. At the completion of the conference, Arrernte Elders named the meeting Anwernekenhe, which translates as 'Us Mob' in Arrernte language.

Anwernekenhe 1 is now recognised as a key milestone in the Aboriginal and Torres Strait Islander led-response to HIV. There have now been six Anwernekenhe conferences, and to mark 21 years since the inaugural 1994 meeting, Anwernekenhe 6 – held in November 2015 – saw the conference return to its original location in Alice Springs. Twenty-one years on, the key recommendations from the 1994 conference still enshrine the core objectives of the Aboriginal and Torres Strait Islander

response to HIV: 'Us mob stronger together, working to stop HIV for our people and our country'.<sup>2</sup>

## Advocacy and activism – the early years

In the early days of the HIV response in Australia, many Aboriginal and Torres Strait Islander gay men and sistersgirls considered themselves to be invisible as a priority group. Misconceptions about homosexuality in Aboriginal and Torres Strait Islander culture, compounded with limited understanding of HIV risk factors and infection, resulted in discrimination and isolation.

Community concern about the impact of HIV/AIDS among the Aboriginal gay population in the early 1980s saw a support network established by a group of openly gay Aboriginal men that included Rodney Junga-Williams, Malcolm Cole, Mathew Cook, Luke Close and John Cross. In 1992, the First National Aboriginal HIV/AIDS Conference was held. This conference identified an urgent need to better understand and respond to the HIV/AIDS issues for gay men and sistersgirls.

In April 1994, following a meeting of national HIV/AIDS educators in Sydney, John Cross, who was working as the Gay Men's Peer Educator at Central Australian Aboriginal Congress (Alice Springs), with assistance from Phil Walcott from the AIDS Council of Central Australia, collaborated to prepare a successful funding submission to the Commonwealth to develop a national conference specifically addressing the impact of HIV in the Aboriginal and Torres Strait Islander gay and sistersgirl community.<sup>3</sup> Shortly after, in

June 1994, a National Steering Committee was established to guide and oversee conference planning.

## Anwernekenhe 1: 31 October – 4 November 1994

Unlike recent Anwernekenhe conferences, held in city conference centres with all the trappings, Anwernekenhe 1 took place in the open air at Hamilton Downs, Alice Springs. (See p.13 for excerpts from Neville Fazulla's beautiful evocation of that first conference.)

Conference deliberations initially focused on HIV and sexual health; however, as the conference progressed the agenda expanded to include broader health issues such as mental health, alcohol and substance abuse, sexual abuse, adoption and fostering issues, and the needs of transgender people.

Conference participants together developed a set of recommendations that were presented to a representative of the Australian Federation of AIDS Organisations (AFAO) on the last day of the conference. A further key outcome of Anwernekenhe 1 was the establishment of the National Aboriginal and Torres Strait Islander Gay Men's and Transgender Working Party, which was given the responsibility of progressing Anwernekenhe 1 conference recommendations.

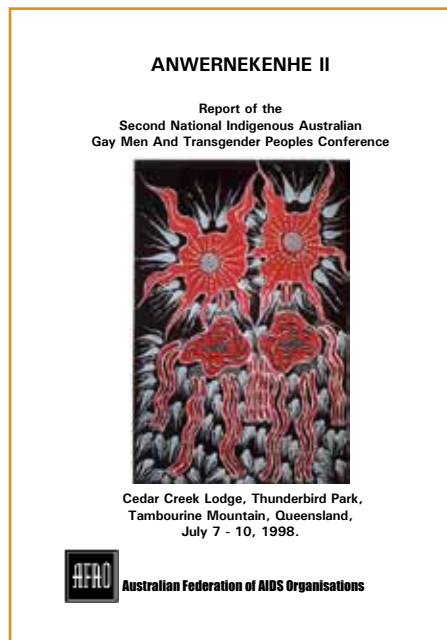
Recognising the devastating impact of HIV among the gay and sistersgirl community, and the need to formulate actions to safeguard the community's future was the impetus for Anwernekenhe 1, and the conference evaluation report noted that the conference process had built 'a clear sense of belonging and dedication to process'<sup>4</sup>. Participants prioritised further exploration and commitment to developing strategies for dealing with education, prevention, care and support for Aboriginal and Torres Strait Islander communities and HIV.

The Anwernekenhe movement – an Aboriginal and Torres Strait Islander

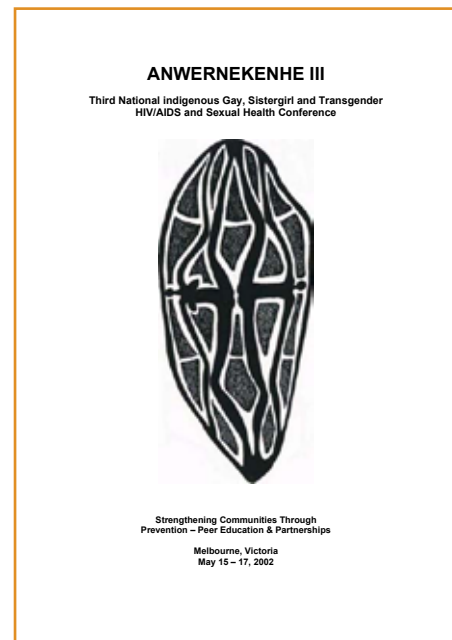
At the completion of the conference [Anwernekenhe 1], Arrernte Elders named the meeting Anwernekenhe, which translates as 'Us Mob' in Arrernte language.



Anwernekenhe 1 (1994) conference report; front cover art by Rex Murray.



Anwernekenhe 2 (1998) conference report; front cover art by Rex Murray.



Anwernekenhe 3 (2002) conference report; front cover art: *Us Mob* by Arone Meeks.

community movement established to effect change in the Australian HIV response – had begun. Conference participants united in creating a model of self-determination for Aboriginal and Torres Strait Islander people affected by HIV.

By 1996, the National Aboriginal and Torres Strait Islander Gay Men's and Transgender Working Party (now a steering committee) was actively operating as part of the Australian Federation of AIDS Organisations (AFAO) advisory structure. Later that year, AFAO received Commonwealth funding to establish the AFAO National Aboriginal and Torres Strait Islander Gay Men's and Transgender Sexual Health Project, which was commissioned to progress the Anwernekenhe 1 recommendations.

The project commenced in early 1997, with the employment of Gary Lee as the project coordinator. Between early 1997 and June 1998, the project conducted national consultations with the Aboriginal and Torres Strait Islander gay and transgender community, including consultations with AIDS Councils and Aboriginal Community Controlled Health Services. Outcomes and corresponding strategic responses were then published as part of the *National Indigenous Gay and Transgender Project Consultation Report and Sexual Health Strategy*.

### Anwernekenhe 2: July 1998

The Consultation Report and Sexual Health Strategy was ratified and endorsed

by conference delegates at Anwernekenhe 2 in July 1998. AFAO's National President, Peter Grogan, and Colin Ross (in his capacity as Convenor of the AFAO Indigenous Gay and Transgender Steering Committee), emphasised the significance of the report and strategy, saying: 'We at last have documentation of the reality of HIV for Indigenous gay men and transgender persons that will shape AFAO's ongoing response'<sup>5</sup>. The strategy provided a strong foundation for both AFAO and AIDS Council program and policy responses for well over a decade, and paved the way for effective involvement of gay and sistergirl representation on national and state government and community advisory structures.

The strategy and recommendations resulting from Anwernekenhe 2 also laid groundwork for the staging of the First National Indigenous Sistergirl Forum on Magnetic Island in 1999. The forum provided a much needed space for sistergirls to come together and develop HIV and sexual health strategies addressing isolation, violence, low levels of HIV awareness and self-esteem. Significant actions from this event saw Aboriginal identified positions created in AIDS Councils, sistergirl sexual health retreats, first time inclusion of sistergirl terminology in the Second National Aboriginal and Torres Strait Islander Sexual Health Strategy, and implementation of the very successful AFAO campaign *Sistergirls Say – Keep Yourself Covered*.

### Anwernekenhe 3: May 2002

By Anwernekenhe 3, in 2002, the AFAO National Aboriginal and Torres Strait Islander Gay Men's and Transgender Steering Committee had become known as the AFAO National Indigenous Strategic Alliance (ISA). An independent review of the AFAO National Aboriginal and Torres Strait Islander Project and Steering Committee, completed in 2001, had suggested an expansion of work was needed. A 'whole of community' approach was agreed to, allowing for other Aboriginal and Torres Strait Islander 'at risk' groups and increasing work being undertaken by AIDS Councils.

Anwernekenhe 3 highlighted some worrying emerging trends among Aboriginal and Torres Strait Islander communities such as injecting drug use and the first identified cases of HIV seroconversion in women. In considering how best to address these issues, the ISA commenced a national organisational consultation process to canvass the idea of expanding its work.

The basis for this approach stemmed from the ISA's belief that<sup>6</sup>:

- there were clear policy and service overlaps between what was needed for gay men and sistergirls and what was needed for other Aboriginal and Torres Strait Islander communities
- the ISA had built expertise through its work with gay men and sistergirls and this could be used to benefit other members of Aboriginal and Torres Strait Islander communities



- the ISA had already extended beyond gay men and sisters. Two previous projects included a treatments booklet for all Aboriginal and Torres Strait Islander people with living HIV and a project researching injecting drug use among Aboriginal and Torres Strait Islander communities
- the ISA's links with AFAO and the different parts of the national HIV response meant they were well positioned to offer good representation to all Aboriginal and Torres Strait Islander people affected by HIV. The ISA already had a place at the table in many important parts of the mainstream national HIV response, which it could use to advocate for all Aboriginal and Torres Strait Islander communities affected by HIV.

The ensuing national consultation process provided strong support for the proposed changes. Discussions with the National Aboriginal Community Controlled Health Organisation (NACCHO) emphasised considerations around maintaining an HIV focus. At Anwernekenhe 4, held in April 2006, two strategic ideas were presented to participants for consultation and consideration.

The first was to expand work beyond gay men and sisters and to respond to the needs of other Aboriginal and Torres Strait Islander people who find themselves at risk of HIV. This included:

- women and young people
- people who inject drugs
- people who engage in sex work or sex for favours
- people in custodial settings, and
- mobile/transient populations.

The second proposal was to establish an independent Aboriginal and Torres Strait Islander-controlled organisation solely focused on building and maintaining a comprehensive and effective response to HIV among Aboriginal and Torres Strait Islander communities.

#### Anwernekenhe 4: April 2006

Anwernekenhe 4 deliberations endorsed the strategic change. This represented a major turning point and much hard work followed to bring this to fruition.

In 2008, we became incorporated as the Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance. In 2009 we became the twelfth



Anwernekenhe 4 (2006) conference report; front cover.

organisational member of AFAO, and secured a place on the AFAO Board alongside to other national HIV peaks.

The first Anwernekenhe conference had set many goals, and many had been achieved over the years. But to finally have a strong, independent and incorporated Aboriginal and Torres Strait Islander voice on HIV was a great outcome — it was the realisation of a dream first described at Anwernekenhe 1.

Under no illusions, we recognised that much of the hard work was still to come. In 2006, the Department of Health and Ageing's Office of Aboriginal and Torres Strait Islander Health (OATSIH), changed funding to a tender process, resulting in a shift of the funds. From that point AFAO then directly funded the AFAO Aboriginal and Torres Strait Islander project and the ANA.

At the end of 2010, with limited funding opportunities, the ANA faced the real possibility of winding up the organisation. The ANA Board in partnership with AFAO management initiated discussions with the AIDS Trust of Australia (ATA), successfully securing a grant to implement Anwernekenhe 5.

#### Anwernekenhe 5: August 2011

Anwernekenhe 5 saw the development of the first ever ANA Strategic Plan, providing 11 strategic goals to guide the organisation between 2011 and 2015. Soon after the conference, the ANA also received welcome news of a further grant from the



Anwernekenhe 5 (2011) conference report; front cover art: *Voyage* by Arone Meeks.

ATA, allowing employment of the ANA Executive Officer.

In April 2013, the ANA then received further exciting news that the ANA would receive a three year contract through the Commonwealth Department of Health. The contract and funding have allowed the ANA to consolidate implementation of the strategic plan and development of Anwernekenhe 6.

#### Anwernekenhe 6: November 2015

With the sun setting and in view of Yeperenye, Ntyarlke and Utnerregatye<sup>7</sup> Arrernte Elders and Custodians welcomed just over 100 people to country in Alice Springs, for Anwernekenhe 6. After the welcoming, Neville Fazulla, Chair of the ANA and Anwernekenhe 1 participant delivered the conference chair's address: 'Remembering Our Journey'.

The conference program commenced with a screening of video footage<sup>8</sup> filmed at the inaugural Anwernekenhe 1 conference. The video stirred up strong emotions among the Anwernekenhe 6 participants. The screening allowed us the space to remember those who were not present and to reflect on the work still to be done. Some people spoke about the need to maintain 'a fire in the belly' – a sense of unity and drive needed to continue the work begun by the Anwernekenhe 1 pioneers in forming a strong community voice calling for action on HIV among Aboriginal and Torres Strait Islander communities.



A rapturous standing ovation was given to Associate Professor James Ward after delivering a passionate Anwernekenhe 6 conference keynote address. In no uncertain terms, James outlined the potential for further increases in HIV diagnoses among Aboriginal and Torres Strait Islander people and the appalling rates of sexually transmissible infections (STIs). His keynote address was a mix of hard data and emotion, and a strong call to the Commonwealth to implement the actions set out in the *National Aboriginal and Torres Strait Islander BBVs and STIs Strategy 2014–2017*.

James' speech opened and closed with poignant tributes to Aboriginal and Torres Strait Islander HIV advocates, past and present, with a heartfelt tribute to community members lost to HIV and AIDS.

Anwernekenhe 6 conference participants included Aboriginal and Torres Strait Islander peer groups of people living with HIV, gay men, sistergirls, brotherboys, sex workers and people who inject drugs, alongside approximately 30 sexual health workers – all coming together to discuss, debate and share experiences about the direct impacts of HIV. Priority issues focused on awareness, prevention, testing, treatments, care and support and stigma and discrimination. Through these deliberations, participants actively contributed to the development of the ANA's second Strategic Plan 2015–2019, setting out a series of priority actions.

The conference closed with presentations encapsulating the conference theme of remembering, recognising and responding. Elders Aunty Matilda House and Aunty Joan Lamont warmly shared personal and collective stories, remembering loved ones, and historical and cultural events.

AFAO Policy and Communications Manager Linda Forbes gave a strong speech on the enduring partnership that has existed between AFAO and the ANA since Anwernekenhe 1 (see page 63). Neville Fazulla acknowledged the hard and dedicated work of Aboriginal and Torres Strait Islander sexual health and community peer workers, noting that the important impact their work has had on the health and wellbeing of Aboriginal and Torres Strait Islander people.

Fittingly, the final conference presentation came from youth representative, Caleb Nichols-Mansell. Caleb delivered a

## Remembering our journey: Anwernekenhe 6 opening address

By Neville Fazulla

**On Thursday 12 November, Anwernekenhe National HIV Alliance (ANA) Chair, Neville Fazulla, officially opened the Anwernekenhe 6 conference in Alice Springs.**

**In his address, Neville shared his recollections of the formation of the Anwernekenhe movement and paid tribute to the founders and pioneers of Anwernekenhe 1, some of whom were present for the sixth conference, which marked Anwernekenhe's 21st anniversary.**

**Below are some brief excerpts from Neville's address, where he describes the beginnings and the significance of the inaugural Anwernekenhe event.**



'Back in 1993, there were a group of us that were very aware on what was going on in the HIV environment, how that was having an impact on the gay and sistergirl community in Australia. What happened was, there was a conference up in Alice Springs in 1992, which was an Aboriginal sexual health conference. That conference had some members of the Aboriginal, gay, lesbian and sistergirl community attend it, but we were in a sense not on the agenda and ostracised. Some of our brothers had travelled overseas and seen what was happening overseas, and programs happening there, and came back and started a discussion.

We went to the Commonwealth for funding; John, along with Colin and Rodney<sup>1</sup> coordinated that process, and we were successful in getting funding to hold a conference. It was only a small amount of funding, but the spirit of the people who came to the conference proved too powerful to worry about the money.

The first Anwernekenhe conference was held in a creek bed. We'd invited AFAO (who was still based in Canberra at the time) to attend and see what we were doing, and how we could liaise with them. They turned up on the Thursday morning, and we were all paying volleyball and sitting around, putting on makeup and doing different things.

Every night we'd have a deadly disco run on a car battery. We got into trouble with the man who was running the homestead because he would turn the lights off at 10 o'clock every night, and we'd get the car battery and put all the leads on it and light the whole place up and have a big disco until 2 or 3 o'clock in the morning. There was no drugs, no alcohol, but we let 'em know we were there. And in that process, we also wrote a Plan which had 116 recommendations in it.

When the AFAO guys turned up and they could see us all playing around, lying around, doing different things, some of them must've thought, 'Oh ... what've we walked into?' When they walked down, we presented them with the pieces of paper – some of them were hand written and some of them were printed out – and we said: 'That's what we want'. They took it away, read it and agreed to it.

From there, we got the name from the traditional owners around here: Anwernekenhe ('Us Mob'). We took that name; we cherished that name, and we moved forward. From there, we've grown to what we've are today. We've had eight Chairs. We've moved from a project at AFAO to an incorporated organisation that makes our own decisions. When we left Hamilton Downs we were the National Aboriginal and Torres Strait Islander Gay and Sistergirl Forum. We're now the Anwernekenhe National HIV Alliance.

About three months after we left Hamilton Downs with all these Recommendations, we began working with AFAO and we went to the Commonwealth. Our role was the first working party on the first National Aboriginal and Torres Strait Islander HIV Strategy. We're now at the fourth – we've been involved in and informed every single one. The major thing was we got to write our own strategy, in our own way, to address the issues in our community. It was ours. We informed the process and we did it.

We've moved along quite rapidly. In some senses it's been a long time – 21 years – but we've never lost the vision. We've changed the way we've looked. ... we've had to move our boundaries and exteriors to suit what the national environment is, but we've never lost the fact that we're here. It's about us as a community, and it always will be.

We've built capacity for positive people to have a voice at the national level, which is called PATSIN (Positive Aboriginal and Torres Strait Islander Network). We've got the sistergirl movement and forum; we brought in the injecting drug user community, the sex worker community, and men who have sex with men. And we've taken on all those groups within our community and supported them until they can have a voice in their community on their own. Anwernekenhe isn't just about gay men, it's about the community response to HIV.

We showed that we can take the lead and do it in a constructive, community driven way. The work we do isn't just imagined in an office block, it's actually informed by the community. So applaud yourself everybody.

(And much applause there was indeed.)

### Reference

1 John Cross, Colin Ross and Rodney Junga-Williams.

Listen to Neville's full speech online at: [bit.ly/nf-a6](http://bit.ly/nf-a6)



ANTHYM's Caleb Nichols-Mansell delivered the closing statement at Anwernekenhe 6. Photo: Stephen Morgan.

statement on behalf of ANTHYM (the Aboriginal Nations Torres Strait Islands HIV Youth Mob), looking to the future and advocating for increased inclusion and representation of youth in responding to HIV:

*In opening, I would like to acknowledge those elders and seniors who have paved the way and thank them for their tireless work in this sphere.*

*So where to from here? Mentorship is needed from Elders and seniors to empower us youth, so that we can carry on the legacy and work that has been done by those before us. Ensuring those who have already paved the way feel confident in us youth carrying on this movement into the future.*

*Our communities need youth to be included in the discussion around key issues in policy that affect us youth. This includes all peer groups from LGBTI, sistergirls and brotherboys, to injecting drug users and those people that are living with HIV.*

*It's important we're involved in these discussions and decision making, so that all of us in the community – including Elders – understand the issues we face. We need to work together to formulate effective strategies in prevention and awareness to cover emerging issues for our communities.*

*In closing I'd just like to say, us youth need to learn from our Elders just as much as they need to learn from us. We're ready and waiting – we are the present and we are the future.'*

### ANA social event and community awards

Following the tradition of every other Anwernekenhe conference, with business



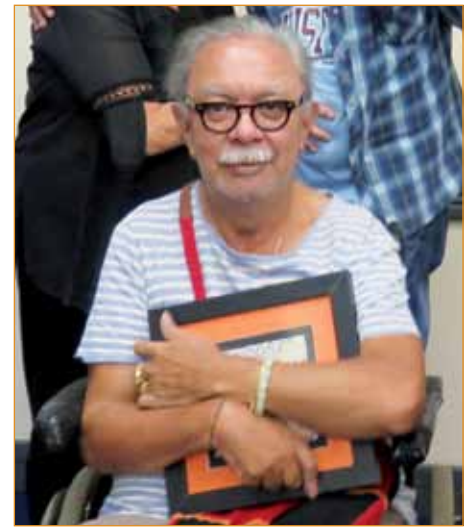
Bev Greet receiving the 2015 Rodney Junga-Williams Memorial Award, presented by Joan Lamont (Rodney's mother).

completed it was time for the conference closing social event, featuring several well-known drag personalities in attendance. Conference goes and many Alice Springs locals were entertained with a jam packed drag show extravaganza. Hosted by Miss Ruby Royal Reserve, the night seemed to just slip away with numbers from Destiny Haz Arrived, Deena Deadly, Townsville Tracey and Queen of the Nullarbor. Music by DJ Corey (who also doubled as the Conference Coordinator) ensured a fun and energetic night was had by all.

The closing social event included the ANA acknowledgment awards in recognition of work and commitment to Aboriginal and Torres Strait Islander communities and HIV. With Anwernekenhe 6 marking 21 years, special recognition awards were presented to all past Chairs of the previous and present ANA committees and Board. The ANA Chairs over the past 21 years included: Colin Ross; Robert (Vanessa) Smith; Gary Lee; Mark Saunders; Dion Tatow; Michael Costello-Czok; Michelle Tobin; and current Chair, Neville Fazulla.

Two inaugural memorial awards were established and will be awarded bi-annually, the Rodney Junga-Williams Memorial Award and the John Cross Memorial Award.

The 2015 Rodney Junga-Williams Memorial Award was presented to Bev Greet. Rodney died in 2011, having dedicated many years to the fight for addressing treatment, care and support issues for Aboriginal and Torres Strait Islander people living With HIV, through leadership and both national and international activism.



Gary Lee, recipient of the 2015 John Cross Memorial Award.

The 2015 John Cross Memorial Award was presented to Gary Lee. John Cross died in April 1995 aged 32. His vision and energy were instrumental in the development of Anwernekenhe 1, a long held dream he shared with fellow advocates.

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- 1 Participants statement in Anwernekenhe 1 conference report. Anwernekenhe. (1994). Anwernekenhe First National Aboriginal and Torres Strait Islander Gay men and Transgender Sexual Health Conference. Anwernekenhe, 9. Retrieved from: [https://www.afao.org.au/\\_\\_data/assets/pdf\\_file/0003/4656/Indig\\_anwernekenhe1.pdf](https://www.afao.org.au/__data/assets/pdf_file/0003/4656/Indig_anwernekenhe1.pdf)
- 2 Vision statement of the Anwernekenhe National HIV Alliance (ANA). For further information see: [www.ana.org.au](http://www.ana.org.au)
- 3 Anwernekenhe. (1994). op. cit.
- 4 ibid.
- 5 Lee, G. (1988). *The National Indigenous Gay and Transgender Consultation Report and Sexual Health Strategy*. AFAO, Sydney. Retrieved from: [https://www.afao.org.au/\\_\\_data/assets/pdf\\_file/0016/4660/Indig\\_report.pdf](https://www.afao.org.au/__data/assets/pdf_file/0016/4660/Indig_report.pdf)
- 6 Indigenous Strategic Alliance (ISA), AFAO. (2003). *ISA and AFAO Strategic Directions Consultation Paper*. ISA, AFAO, Sydney.
- 7 Yeperenye, Ntyarke and Utnerengatye are referred to as the giant caterpillars, the creative ancestors of Mparntwe (Alice Springs) and the Arrernte peoples.
- 8 A film made by Hedimo Santana in 1994. *Anwernekenhe 1*. (1994).

**Michael Costello-Czok is Executive Officer of the Anwernekenhe National HIV Alliance (ANA) and a guest editor of HIV Australia. Neville Fazulla is Chair of the ANA.**



## Anwernekenhe 6 – a brief summary of recommendations



**Anwernekenhe 6 served as an opportunity to celebrate 21 years of Anwernekenhe events. The conference managed to be both reflective (acknowledging past contributions and achievements to date) and forward-looking. Generational change was a key conference theme.**

Participants commenced the conference with yarning circles, and the final workshop session involved three separate group discussions – for women, men, and sistergirls and brotherboys. Each of these groups put recommendations to the conference and there was broad support for their propositions.

The women's session recommended that the Aboriginal and Torres Strait Islander community response to HIV include a stronger focus on women, with this focus reflected in the development of resources (including online information) and health campaigns specific to women. The session argued for improved access to HIV testing via community-based and culturally appropriate services, and for greater participation by youth in all levels of the community response, including through youth participation in the ANA Board.

The men's session recommended strategies for promoting community awareness of HIV – through

proper protocols, collaboration between services, peer education, printed resources, community television, the adaptation of AIDS Council programs (where appropriate), and improved social and emotional wellbeing.

The session called for proactive prevention strategies, better access to rapid HIV testing and more consistency of servicing across communities. It recommended strategies to enhance testing (normalising testing, offering incentives to test, developing resources that use appropriate language, improving inter-service collaboration, training for clinicians and incorporation of testing into annual health checks).

The men's session recommended a range of ways to better link with and engage people living with HIV, including through targeted advocacy, use of the ANA website, and promotion of ANA through Aboriginal Community Controlled Health Services. It also suggested strategies for engaging young Aboriginal men, including involvement of youth in program development and implementation, training and career opportunities for male health workers, support for peer workers and engagement of youth in the ANA Board.

The sistergirls and brotherboys session recommended greater attention to brotherboy

identity in the work of the ANA, a sistergirl/ brotherboy retreat or conference, a poster campaign engaging Elders, and strategic lobbying targeting clinicians, government and other organisations to achieve education, policy and political goals.

The conference also supported a recommendation from the floor proposing that mainstream LGBTIQ (lesbian, gay bisexual, transgender, intersex, queer) organisations take on more responsibility for combatting racism.

An important statement on behalf of youth participants indicated the preparedness of youth to take up the fight, while also seeking inclusion, support and mentoring from Elders, and more opportunities for mutual learning.

A number of recommendations emerged from the yarning circles, including from the women's yarning circle, the gay/men who have sex with men yarning circle and the people living with HIV (PLHIV) yarning circle. The PLHIV yarning circle recommended enhanced HIV education and testing for Aboriginal and Torres Strait Islander people in rural and remote communities, training for prescribers of ART and national uniform access to free HIV medications, with no gap payments required in any jurisdiction.



### On the cover

**Anwernekenhe – 'Us Mob'**, Aunty Gloria Beckett, 2003.

The painting represents the coming together of the Aboriginal and Torres Strait Islander gay men and sistergirls from across Australia, who attended the First National Aboriginal and Torres Strait Islander Gay men and Transgender Sexual Health Conference, held at Hamilton Downs on the 31 October–4 November 1994. The word 'Anwernekenhe' (meaning 'Us Mob') is a name permitted to be used as the respected traditional name for the conference by the Arrernte people, on whose land the conference was held.

Sadly the artist, Aunty Gloria Beckett, passed away in Brisbane in 2003.



Photographs from Anwernekenhe 6, Mparntwe (Alice Springs), Arrernte Nation, 12–14 November 2015.







# The road travelled and the road ahead: Anwernekenhe 6 keynote address

By James Ward

Wert! Let me begin by paying my respects to the traditional owners of country in Mbantua, to their elders both past and present, to Helen Liddle and your extended family – thank you for welcoming us all here on country. To our other Elders in the room, let me pay my respects to you. Alice Springs and its surrounds is a special place for me, it is where my family's ancestors moved and roamed for thousands of years before me.

In writing this speech, I have reflected and pondered what it means for a community organisation like Anwernekenhe (the ANA) to turn 21. What has been? What will be? The road travelled and the road ahead. However, allow me to start a little earlier than Anwernekenhe. I want to begin by going back to 1982.

October 1982 was the year the first HIV case was diagnosed in Australia. After much mayhem and scary media on a daily basis, AIDS was about to get us all, fear was instilled in us all – especially a dreaded fear instilled in gay men. It's probably fair to say that Australia and the world was facing a public health issue it had not seen before. The economy of Australia wasn't that strong, and much effort was put into thinking how we as a community could address HIV. There was no doubt that HIV had caught the world off guard. At this point we were all flying blind.

1982 was also a time when black Australia was finding its way in an Australia that had denied our forebears so much since colonisation. It was only 15 years earlier that

the 1967 Referendum was held, allowing Aboriginal and Torres Strait Islander people to be included in census counts. It was clearly a time when Aboriginal people were finding our feet after an extended period of the White Australia policy. It was a time when much angst existed between our two populations, and furthermore, in our extended GLBTI communities, racism and class were pervasive, and some still see that not much has changed in this regard.

We were faced with a new disease that was having devastating consequences on the people we loved. As a population we were still struggling to regain our rightful place in Australian society.

During these early days of HIV in Australia, much work was put into preventing HIV among particular populations – particularly marginalised groups like sex workers, drug users and gay men. In recognition of what HIV could do to these groups it wasn't long before a response was mounted. In 1986, led by Dr Alex Wodak, Australia's first needle-syringe program (NSP) was trialled in Sydney. By testing returned syringes, this pilot project found an increase in HIV prevalence, suggesting that HIV was already spreading among injecting drug users. In the following years, NSPs became policy throughout Australia as governments realised the provision of sterile injecting equipment was essential to reducing the spread of HIV, in addition to hepatitis B and C. It's clear now that NSPs have saved thousands of Australian lives.

Medicine and science has made some wonderful achievements in HIV. On a global scale it's now thought that by the year 2020 – five years away – 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy (ART); and 90% of all people receiving ART will have viral suppression. This is what's known as the '90-90-90 strategy' – what amazing ambitious leadership and what amazing advances in science. However we have to be very mindful that our communities don't become the 10% that are left behind.

On the treatment side we have moved from a single anti-cancer drug AZT in the early days, to the highly active antiretroviral treatments available to people living with HIV today, and now with drugs even now able to be used to prevent HIV.

The drugs in the early days were horrendous, the side effects noticeable, and although AZT was available, it wasn't easily available and it wasn't nearly half as efficacious as today's drugs are. I have very close friends who were doctors at this time, who spent copious hours filling in paperwork to get medicines prescribed to patients – not as a right, but on the grounds of compassion.

Thankfully, we have moved on.

Now it goes without saying, that many of us have lost our friends, our lovers, our colleagues, our family, and our community members. Australian society is weakened without these people here; they were warriors of their time, and if science was as advanced as it is now they would be still here. They were all taken far too young, far too early, and often, in the prime of their lives. For those of you who survived that period, what amazing people you are, what amazing souls you are, and we are forever grateful – you have so much to share. For you to have seen and lived the suffering, to have felt the loss, to have feared and faced your own mortality, what incredible souls you have, what incredible guardian angels you have looking over you.

... what amazing souls you are, and we are forever grateful – you have so much to share. For you to have seen and lived the suffering, to have felt the loss, to have feared and faced your own mortality, what incredible souls you have, what incredible guardian angels you have looking over you.





James Ward delivers the Anwernekenhe 6 Keynote address, Alice Springs, 13 November 2015.

The beauty of science has made life for people living with HIV easier too – unlike the first decade and a half of HIV in Australia, where our fellow brothers and sisters living with HIV had no way to hide their condition; you would’ve no doubt seen it in movies or on your TV screens in features like *Philadelphia*, *The Ryan White Story*, or, in our context, *Holding the Man*. In those days, people living with HIV were so visibly recognisable by their condition – wasted bodies, the obvious kaposi’s carcinomas. Today it’s almost impossible to tell if someone has HIV or not.

So that brings me to focus on the Indigenous response – and let me begin with our famous Condoman who first came to light in 1987 by a group of Indigenous health workers in Townsville. The campaign sought to promote and encourage condom use among Aboriginal and Torres Strait Islanders. The popularity of Condoman has increased over the years. The campaign used humour and messaging that impacted the population it touched on the taboo subjects of sex and injecting. Prompted by the Grim Reaper ads a year earlier, Prof Gracelyn Smallwood advocated for Commonwealth funding because she feared our mob

would miss out on the messages seen on TV then or not make sense of the Grim Reaper ad.

Our own leadership was strong, if you go back to the 1989, when the first ever National Aboriginal Health Strategy (NAHS) was launched. The leadership group who wrote NAHS clearly knew what effect HIV/AIDS could have in our communities. It outlined strategies for Aboriginal Health Workers to be skilled up in prevention, as well as strategies for testing and treating and caring for people living with HIV.

1994, just a few years later, and Anwernekenhe’s birth occurred in Hamilton Downs some 120kms up north east of here; a roundtable of sorts, a gathering of minds, a gathering of leaders, coordinated by my good friend Phil Walcott (who incidentally still lives here in the Alice) and the late John Cross. And so the journey began of Australia’s community-led response to HIV by Aboriginal and Torres Strait Islander people.

Many of you were at the Anwernekenhe 1 conference, and some of those at this first meeting have passed on, and some are

not able to be here this week to celebrate. And so, here you are today 21 years later at Anwernekenhe 6, pondering the path ahead and celebrating the past, which was grim for some in those early days, best demonstrated by the late Prof Fred Hollows in 1992 when he spoke at the first ever National Aboriginal HIV/AIDS Conference here in Alice Springs, and argued that some areas of the AIDS campaign were being inadequately dealt with at the time. In his work he had observed the spread of AIDS in contemporary African communities, and he was concerned that AIDS would spread as vehemently through Aboriginal communities. Gladly, we are testament that that hasn’t been the case but it doesn’t mean he was wrong! The chances of this happening are as real today as they were then.

Our survival has been strong, the emergence of community orgs such as Outblak was born 20 years ago – a gay and lesbian social group in Melbourne that was developed to provide a space for gay men and their friends in Melbourne, and is still a great community event in Melbourne.

For me personally, a lot has changed. I have been involved in the development of the

HIV response – particularly in this setting – for many years. I remember working here in Alice Springs in the late 1990s, creating video tapes in central Australian Aboriginal community languages about HIV.

ANA's role in the past 21 years has been focused on responding to the community, developing campaigns for the community, supporting staff working in mainstream organisations, advocating for change within AIDS Councils, supporting the development of policy and practice, membership of national committees within the HIV partnership. It's an important role, and one that needs to be continued. It's unacceptable that right now that ANA, like many other community-based organisations, are struggling with long-term funding commitment from governments.

So what does the future hold for us as a community?

I am here to say this – if we are not careful we will end up with rates of HIV similar to African countries like Nigeria. You might ask 'Why?' My response is because it's happened in similar populations to us, such as in First Nations Aboriginal people in Canada. Let me just point to one province in Canada, Saskatoon, where the rate of HIV is equivalent to a rate of HIV in Nigeria. Saskatoon is a prairie province, and 16% of its population is Aboriginal. The province has over 600 cases of HIV, in which 80% of them are Aboriginal and 75% of which have been driven by injecting drug use. Because of the high rates of HIV in Saskatoon, the healthcare system is struggling to help all the people affected. This is very possible in Australia, as we have a similar healthcare system and have seen similar scenarios in the past on many other health conditions.

Back in 1998, Australia first started collecting epidemiological data about cases of HIV in the Aboriginal and Torres

Strait Islander community. We have had collectively about 600 cases of HIV diagnosed in our population over the years. The rates of HIV have been on par with the Australian population for most of that time, but in the last few years the rate of HIV diagnosis has been creeping above the non-Indigenous population. It's worrying, it's concerning, but we have failed to get this up in national priorities. People, I hope one day, will see the risk. It would be much wiser to respond now, rather than once something has happened.

So what do we need to do to prevent this from happening?

To me, we have a handful of issues that require strengthening in our response. The first of these is the high rates of other STIs that exist in many Aboriginal and Torres Strait Island communities. With over 50% of young people living in remote communities diagnosed with either chlamydia, gonorrhoea or trichomoniasis, we need to do something urgent and drastic to reduce these rates. It's well established that if you have another STI it makes it much easier for HIV to be transmitted – this is of major concern.

On the subject of other STIs, right now in Australia and among our people, we have the largest syphilis outbreak recorded for over 30 years. This outbreak started out from an initial few cases in Queensland and has now spread to over 800 cases in northern Australia, spanning three jurisdictions. This outbreak mostly affects young people heterosexual people. We have much to learn from this syphilis outbreak – but the main point is if we don't get on top of HIV quickly, once it's diagnosed in communities we will be up the river without a paddle.

We must do more to control STIs in our communities; it's unacceptable, it's appalling – our people deserve better. I don't think we are all that prepared for

outbreak responses once HIV is detected in communities.

The second area of HIV prevention that needs strengthening is in the area of injecting drug use (IDU) within our population. With 16% of all cases of HIV diagnosed over the last five years in the Aboriginal and Torres Strait Islander population attributable to IDU, something is going wrong in our population. We have new drugs like ice; we have risk factors never contemplated before; we have contestable ideas about harm minimisation programs in communities – we need to be doing more.

The third area is through the transmission of HIV from regions on Australia's doorstep. PNG is on the doorstep of the Torres Strait Islands (TSI), and the TSI are on the doorstep of Cape York – an entry point to the rest of Australia. We need to do much more in this space.

Another area we need to do more about is our work with gay men. Survey data have shown differing risk factors in both sexual risk behaviours and injecting risk between Aboriginal and Torres Strait Islander men and non-Indigenous men.

The emergence of sistergirl and brotherboy communities also raises issues into the future about risk prevention strategies.

So too for people living with HIV – the new science of starting people on treatment as soon as possible is compelling for better lives and healthier outcomes. How can we ensure people within our communities are tested, diagnosed engaged in care, on treatment and attain a sustained undetectable viral load?

Finally, we need to address stigma and discrimination. There is a subtle type of discrimination that exists in our communities, sometimes between black and white, sometimes between HIV positive and negative, sometimes between non-drug user and drug users, sometimes between gay and non-gay, and sometimes between genders. Stigma and discrimination drive risk, and we must make these connections and tackle these issues head on. There is much that needs to be done in this space and ANA is ideally placed to tackle these issues.

The establishment of ANTHYM (Aboriginal National Torres Strait Islander Youth Mob) is great for our sector – a

... but in the last few years the rate of HIV diagnosis has been creeping above the non-Indigenous population. It's worrying, it's concerning but we have failed to get this up in national priorities. People – I hope one day will see the risk. It would be much wiser to respond now rather than once something has happened.





youth-led initiative for youth is what is desperately needed. We desperately need to find a space within the response for ANTHYM.

If we could do all of these things well – and do them now – then HIV would still be one of the best stories in Aboriginal health in another 30 years.

The prevention toolbox comprises more than just condoms now. Of course, condoms are a mainstay in prevention efforts; however, treatment is now considered a major tool in the prevention toolbox. The science is clear; the earlier you start antiretroviral treatment the longer you will live. If you are on treatment, the science is that you can enjoy a life with an undetectable viral load, and once again enjoy sexual liberation with your loved ones.

PrEP (pre-exposure prophylaxis) offers us great opportunities again to enjoy the sexual freedom we once enjoyed. This is promising; however, we need to stop and consider and challenge what this will mean to a community with already STIs at too higher levels and nuance the messaging around this to make sure we don't escalate STIs in our urban and regional areas.

Similarly, HIV rapid tests are an incredibly welcome tool to the HIV sector.

ANA's role in the Australian response is real, it's one that is needed, and it's one that needs to be supported. The mantra of 'Nothing About Us Without Us' is pertinent. ANA is made up of representatives of the community affected by HIV and this community conference is important not only as an update for you, but for the rest of your communities.

History tells us now more than ever we need to change. We need to review our efficiency; we need to review our effectiveness; we need to tackle HIV prevention differently. We need to ensure our services that we expect so much from can deliver what is expected of them, and what is required of them in delivering on clinical guidelines.

Because, despite all the advances in science and all the knowledge in the world, a cure for HIV is not yet in our scope.

We need to be sophisticated in our approaches. We need to be on top of what is happening in our communities. We need to be alerting people what the story is in our communities – because responding afterwards is too late.

In closing, I want to acknowledge the contribution Michael [Costello-Czok] has given to this component of the approach within our communities. It's a milestone

that has to be celebrated. Your commitment is commendable. I know it hasn't been an easy path.

Finally, in closing, it would be remiss of me not to mention two others: Neville Fazulla and Rodney Junga-Williams. Connected through kin, connected through blood, I love you both dearly. I miss you like crazy, Rodney, and I am sure you are watching down us today and would be ever so proud of both of our efforts. And to Neville, you're the essence of bravery, courage, strength, love and compassion. I know you work tirelessly, and I know you're committed. I want to acknowledge your efforts, not only at this conference, but over the last thirty years. You're a star.

And on that note, thank you.

**Associate Professor James Ward is Head, Infectious Diseases Research Aboriginal and Torres Strait Islander Health at South Australian Health and Medical Research Institute (SAHMRI).**

Listen to James Ward's complete Anwernekenhe 6 keynote address online: [bit.ly/jw-a6](http://bit.ly/jw-a6)

# Aboriginal Nations Torres Strait Islander HIV Youth Mob (ANTHYM)

By James Saunders

ANTHYM is the first National Aboriginal and Torres Strait Islander Youth Committee focused on sexual and reproductive health education for this generation and future generations. ANTHYM will empower young people as they transition to adulthood through education and a greater understanding of healthy sexual lives. This will involve halting increasing rates of HIV and other sexually transmissible infections, reducing risks associated with early sexual debut using a peer led holistic based approach.

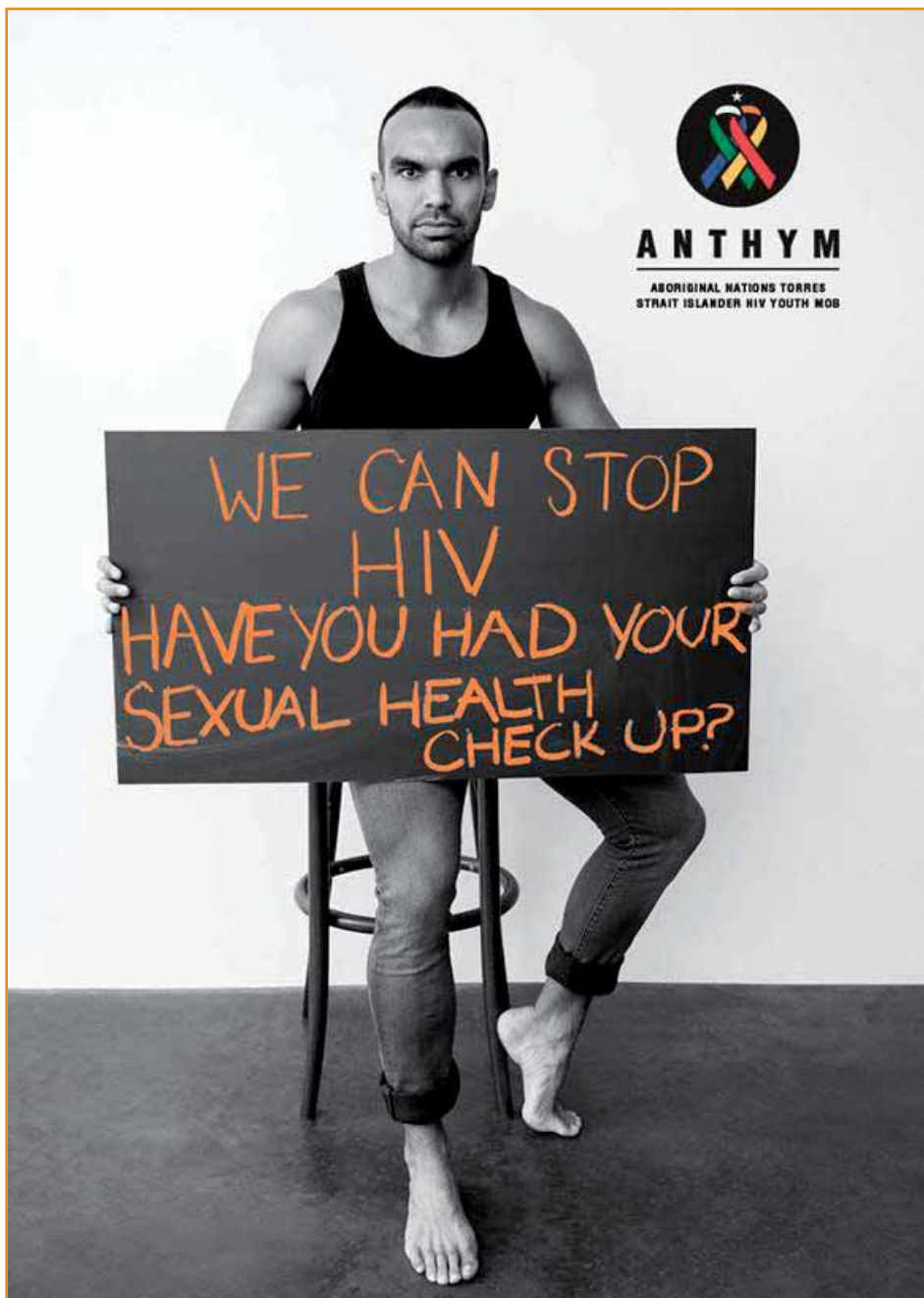
ANTHYM currently consists of 10 passionate Aboriginal and Torres Strait Islander youth who are nurses, university students, and health workers with one thing in common – changing the face of health education and promotion to ensure it has reach, meaning and empowering messages for young Aboriginal and Torres Strait Islander people.

ANTHYM was formed during the 2014 International Indigenous Peoples Conference on HIV/AIDS held in Sydney in July 2014 and a satellite conference of International AIDS Conference held in Melbourne. James Ward was instrumental in the formation of ANTHYM, and we are very grateful for his guidance and mentorship.

Using modern methods of communication, ANTHYM is planning to build a national youth network database of young Aboriginal and Torres Strait Islander peoples who are passionate about changing the conversations about sexual health in their communities. This is one of many projects planned for 2016.

Upon formation, ANTHYM produced a photographic series using catchy slogans to encourage young Aboriginal and Torres Strait Islander people to get tested. The campaign was shot in Sydney with young upcoming Aboriginal models from around Australia volunteering their time to take part in the campaign.

**For further information about ANTHYM and to see more ANTHYM campaign images visit: [www.anthym.org](http://www.anthym.org) and [www.facebook.com/ANTHYMAUS](https://www.facebook.com/ANTHYMAUS)**



James Saunders is a founding member of Aboriginal Nations and Torres Strait Islander HIV Youth Mob (ANTHYM).



# HIV and sexually transmissible infections among Aboriginal and Torres Strait Islander people: summary of the latest surveillance data

By Marlene Kong and James Ward

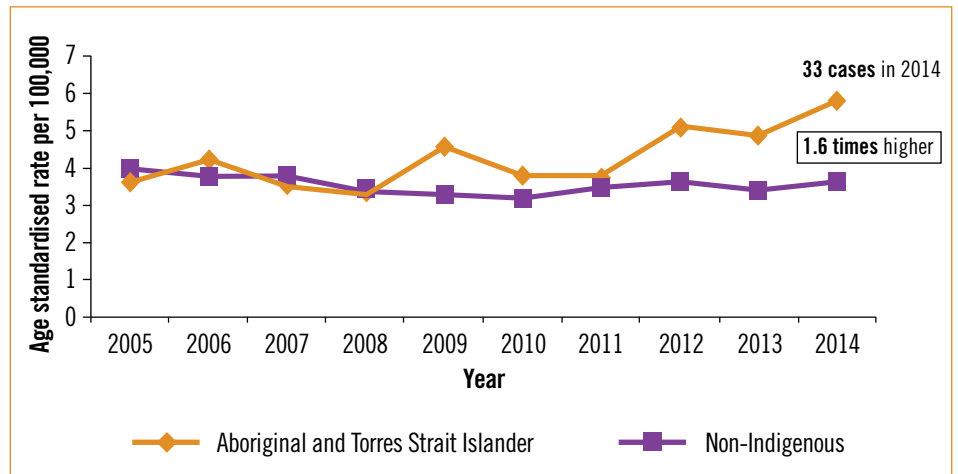
The Aboriginal and Torres Strait Islander Health Program was established at The Kirby Institute in 2007. The Program works collaboratively across sectors to close the gap in health disparity between Aboriginal and Torres Strait Islander and non-Indigenous people, with a key focus on sexual health and blood borne viruses. Each year, the Aboriginal and Torres Strait Islander Health Program collaborates with the Surveillance Evaluation and Research Program on the Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander people: Surveillance and Evaluation Report.

The surveillance report provides information on the occurrence of blood borne viruses and sexually transmitted infections among Aboriginal and Torres Strait Islander people in Australia for the purposes of stimulating and supporting discussion on ways forward in minimising the transmission risks, as well as the personal and social consequences of these infections within Aboriginal and Torres Strait Islander communities. This article has drawn information from that report to provide a summary of the latest surveillance data pertaining to HIV and sexually transmissible infections (STIs).

Australia's Aboriginal and Torres Strait Islander population continues to be overrepresented in notifications of STIs, and blood borne viruses (BBVs). In particular, outer regional and remote communities continue to experience substantially higher rates of notifiable STIs. The information that follows is a summary surveillance data related to STIs and HIV recorded for Aboriginal and Torres Strait Islander communities for the period 1 January–31 December 2014.

## HIV

There were a total of 1,081 notifications of newly diagnosed HIV infection in 2014; 33 diagnoses were among the Aboriginal and Torres Strait Islander population (Figure 1).



**Figure 1:** Newly diagnosed HIV notification rate in the Australian-born population per 100,000, 2005–2014, by Aboriginal and Torres Strait Islander status. Source: State and Territory health authorities; ABS Catalogues 3101051 - 3101058; 3100D0003\_201212; 32380do001\_2011.

242 cases of HIV infection were newly diagnosed in the Aboriginal and Torres Strait Islander population in the ten years from 2005 to 2014.

Between 2012–2014, the notification rate of new HIV diagnosis in the Aboriginal and Torres Strait Islander population (5.9 per 100,000) was higher than in the non-Indigenous population (excluding people from a high HIV prevalence country of birth) (3.7 per 100,000).

The notification rates of newly diagnosed HIV infection in the Aboriginal and Torres Strait Islander population are based on small numbers, and may reflect localised occurrences rather than national patterns.

Among notifications of newly diagnosed HIV infection in 2010–2014, the most frequently reported route of HIV transmission was sexual contact between males in both the Aboriginal and Torres Strait Islander (50%) and non-Indigenous population (75%).

A higher proportion of notifications from the Aboriginal and Torres Strait Islander populations were attributed to injecting drug use (16% vs 3%) and heterosexual contact (20% vs 13%) and in females (22% vs 5%), as compared with the non-Indigenous population (Figure 2, overleaf).

Based on tests for immune function, a third (30%) of the new HIV diagnoses among the Aboriginal and Torres Strait Islander population were determined to be late, in that they were in people who had their infection for at least four years without being tested.

In 2014, HIV prevalence in Aboriginal and Torres Strait Islander peoples was similar to the Australian born non Indigenous population (0.11 vs 0.13%).

The higher rate of HIV diagnosis in Aboriginal and Torres Strait Islander peoples in the past five years requires a strengthened focus on prevention in this vulnerable population (Figure 3, overleaf).

## Chlamydia

Chlamydia continues to be the most frequently reported condition in Australia, with 86,136 notifications in 2014.

Of these, 6,641 (8%) were among the Aboriginal and Torres Strait Islander population; 25,365 cases (29%) were among the non-Indigenous population; and for 54,130 (63%) diagnoses, Indigenous status was not reported.

Over the last five years, chlamydia notification rates in the Aboriginal and Torres Strait Islander population have been

around three times higher than the rate in the non-Indigenous population (Figure 4).

Chlamydia predominantly affects people aged 15–29 in both Indigenous and non-Indigenous populations, with the highest notification rates occurring among women in the 15–19 year age group.

This may reflect greater disease burden, and/or higher rates of access to health services and subsequent testing in these populations (for example, antenatal screening in the younger child-bearing population pyramid of the Aboriginal and Torres Strait Islander population).

Despite just 22% of the Aboriginal and Torres Strait Islander population residing in remote areas, chlamydia notifications reported from these areas accounted for more than half of all notifications in the Aboriginal and Torres Strait Islander population (Figure 5).

### Gonorrhoea

Of 15,786 notifications of gonorrhoea in 2014, 3,584 (23%) were among the Aboriginal and Torres Strait Islander population; 6,915 (44%) were among the non-Indigenous population; and for 5,287 (33%) notifications, Indigenous status was not reported.

The rate of gonorrhoea notifications in the Aboriginal and Torres Strait Islander population in 2014 was 18 times higher than in the non-Indigenous population (Figure 6). 71% of cases among the Aboriginal and Torres Strait Islander population were diagnosed among people in the 15–29 year age group, compared with 56% in the non-Indigenous population (Figure 6).

For the Aboriginal and Torres Strait Islander population, gonorrhoea is mostly diagnosed among young women and men living in remote areas, while the majority of cases of gonorrhoea in the non-Indigenous population are among gay men living in major cities.

This creates two distinct gonorrhoea epidemics in Australia, each of which requires separate responses (Figure 7).

### Infectious syphilis

Nationally, 1,999 cases of infectious syphilis were diagnosed in 2014; 235 (12%) among the Aboriginal and Torres Strait Islander population, 1,588 (79%) among the non-

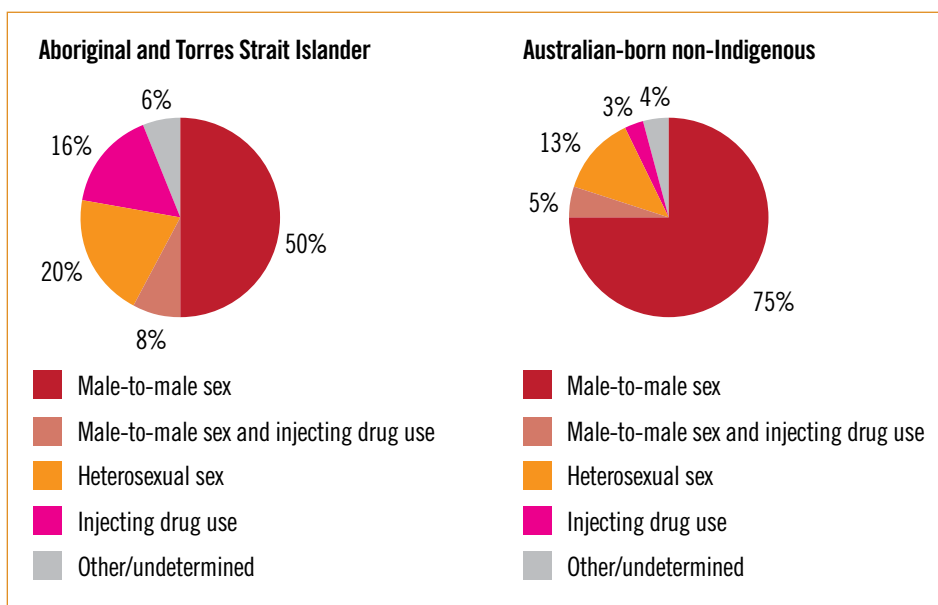


Figure 2: HIV exposure category, 2010–2014, by Aboriginal and Torres Strait Islander status. Source: State and Territory health authorities.

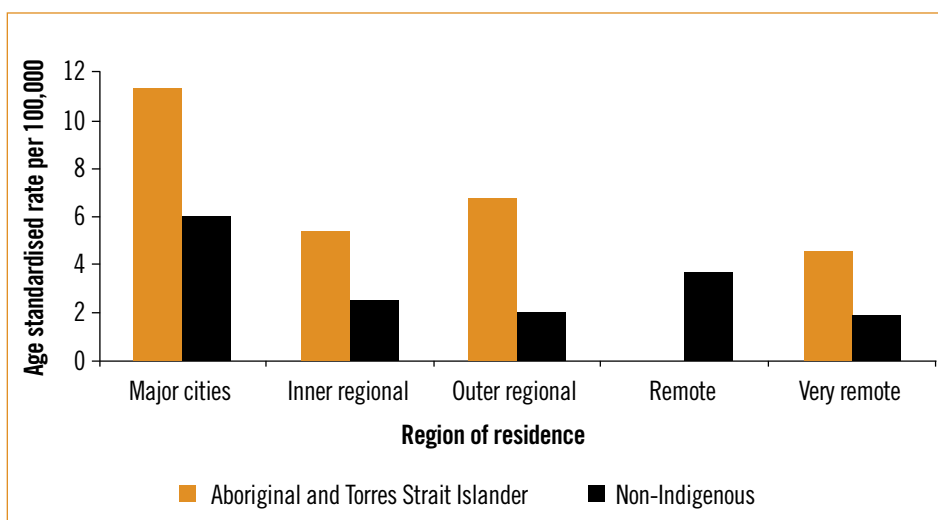


Figure 3: Newly diagnosed HIV notification rate in the Australian-born population per 100,000, 2014, by Aboriginal and Torres Strait Islander status and area of residence. Source: State and Territory health authorities.

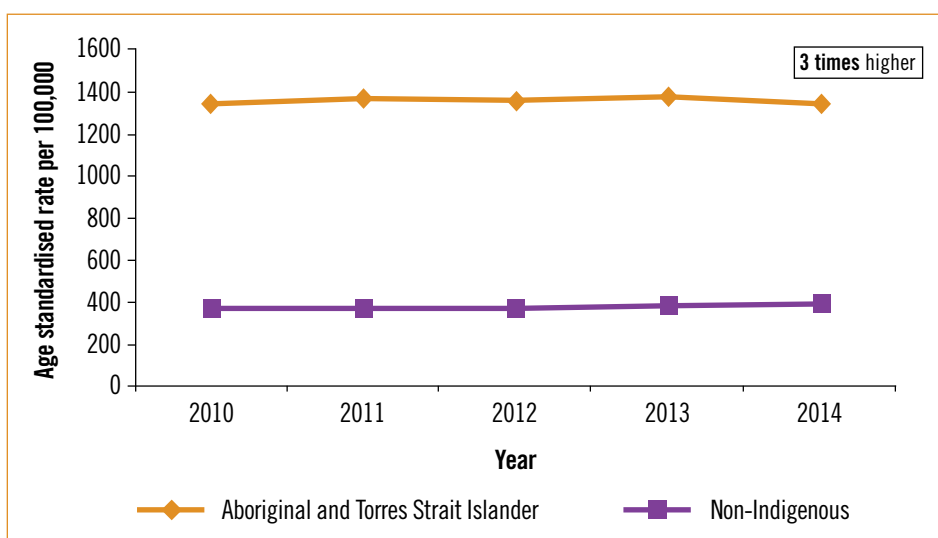


Figure 4: Notification rates per 100,000 of chlamydia infection, 2010–2014, by Aboriginal and Torres Strait Islander status and year. Source: Australian National Notifiable Diseases Surveillance System; ABS Catalogues: 3101051 - 3101058; 3100D0003\_201212; 32380do001\_2011; Includes jurisdictions (NT, QLD, SA, WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses for each year.



Indigenous population and Indigenous status was not reported for 176 (9%) diagnoses.

The notification rate of infectious syphilis in the Aboriginal and Torres Strait Islander population in 2012 was four times higher than the rate in the non-Indigenous population (32 vs 8 per 100,000 population) increasing to 300 times higher in remote areas (Figure 8, overleaf).

Rates of infectious syphilis notifications among the Aboriginal and Torres Strait Islander population increased in 15–19 year olds in 2011 (from 34 per 100,000 in 2010 to 95 per 100,000 in 2011), due to an outbreak in the northern areas of Queensland, the Northern Territory and Western Australia, and was 99 per 100,000 in 2014 (Figure 8, overleaf).

Like gonorrhoea, infectious syphilis affects two main population groups: young Aboriginal and Torres Strait Islander women and men equally in remote communities, indicating predominantly heterosexual transmission; and gay men living in major cities suggesting that transmission is primarily related to sex between men.

Notifications of congenital syphilis in Aboriginal and Torres Strait Islander peoples declined from seven in 2005 to one in 2009, and then returned to 5 in 2014.

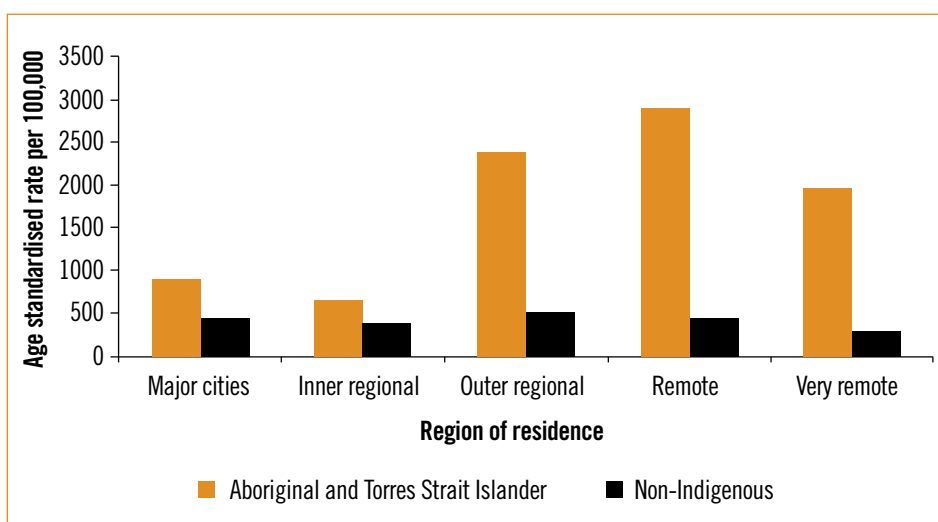
The resurgence of infection in remote communities after years of declining rates, bringing with it cases of congenital syphilis, emphasises the need for testing and treatment in this population, particularly in antenatal settings (Figure 9, overleaf).

### Donovanosis

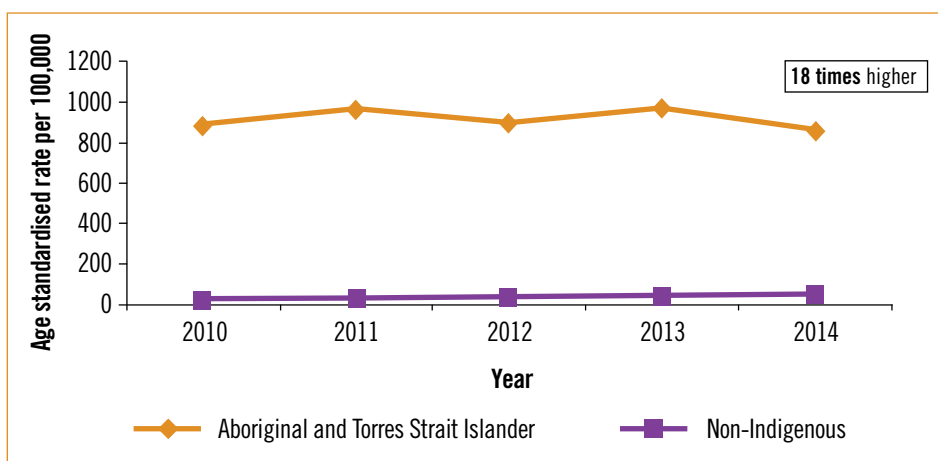
Donovanosis, once a regularly diagnosed sexually transmissible infection among remote Aboriginal populations, is now close to elimination. After a peak in the late 1990s and early 2000s, no cases were detected in Australia in 2011; only one in 2012; zero in 2013; and one in 2014.

### Implications for Aboriginal and Torres Strait Islander communities

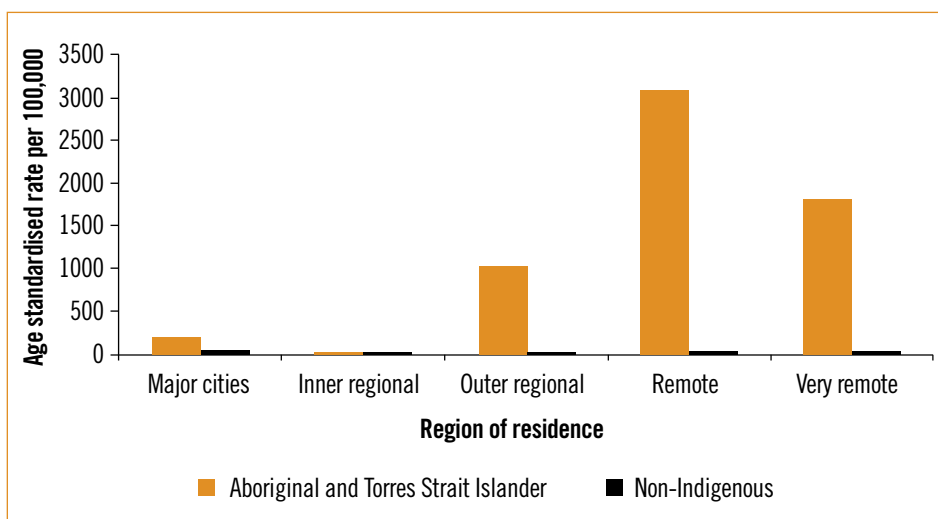
Rates of STIs are particularly high among both Indigenous and non-Indigenous young people living in outer regional and remote areas of Australia; however, it is important to note that rates of chlamydia notifications are higher across all



**Figure 5:** Chlamydia infection notification rate per 100,000, 2014, by Aboriginal and Torres Strait Islander status and area of residence. Source: Australian National Notifiable Diseases Surveillance System; ABS Catalogues: 3101051 - 3101058; 3100D0003\_201212; 1270055006\_CG\_POSTCODE\_2012\_RA\_2011; ABS SuperTable 2011 Census; 32380do001\_2011; Includes jurisdictions (NT, QLD, SA, WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses for each year.



**Figure 6:** Gonorrhoea notification rates per 100,000, 2010–2014, by Aboriginal and Torres Strait Islander status. Source: Australian National Notifiable Disease Surveillance System; ABS Catalogues: 3101051 - 3101058; 3100D0003\_201212; 1270055006\_CG\_POSTCODE\_2012\_RA\_2011; ABS SuperTable 2011 Census; 32380do001\_2011; Includes jurisdictions (ACT, NT, SA, Tas., Vic., WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses for each year.



**Figure 7:** Gonorrhoea notification rate per 100,000, 2014, by Aboriginal and Torres Strait Islander status and area of residence. Source: Australian National Notifiable Disease Surveillance System; ABS Catalogues: 3101051 - 3101058; 3100D0003\_201212; 1270055006\_CG\_POSTCODE\_2012\_RA\_2011; ABS SuperTable 2011 Census; 32380do001\_2011; Includes jurisdictions (ACT, NT, SA, Tas., Vic., WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses for each year.

geographical locations for the Aboriginal and Torres Strait Islander population compared to the non-Indigenous population. Two distinct epidemics exist for gonorrhoea and syphilis and urgent action is required to address levels of knowledge, community awareness and understanding of STIs as well as promotion of testing as a prevention strategy in these communities. In addition, further resourcing is required to assist health services address the burden of disease in these communities.

Internationally, high rates of STIs in communities implicate higher HIV notification rates; however, so far this is not the case in Australia, where rates of HIV diagnoses among the Indigenous population have been comparable to the non-Indigenous population; however, the trend in recent years of higher rates of HIV occurring in the Aboriginal and Torres Strait Islander population than non-Indigenous Australians is worrying.

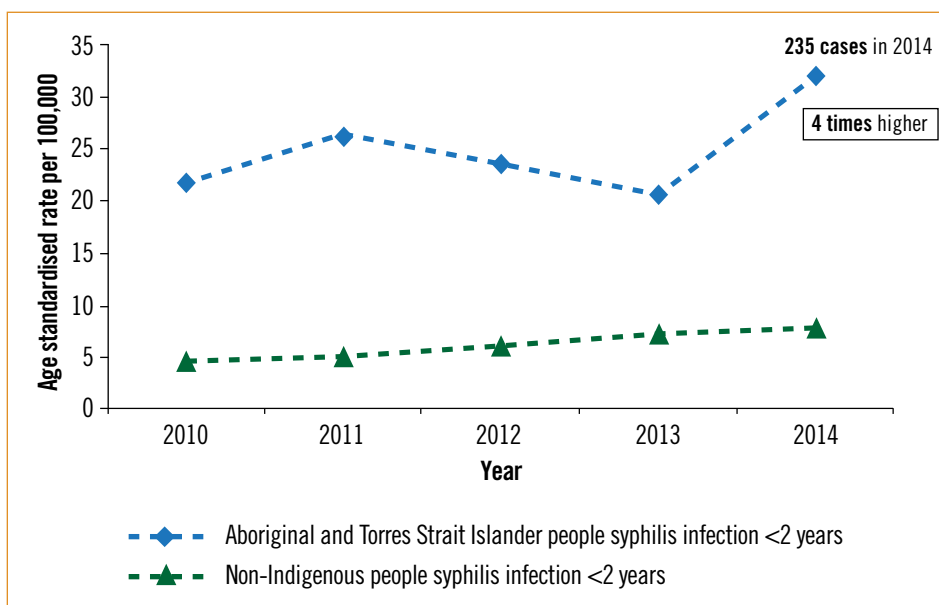
The stigma surrounding HIV continues to be a key driver of HIV transmission, undermining HIV prevention efforts. STIs can also have significant physical, psychological and social consequences, especially for young people, who may shy away from seeking health care. Addressing stigma and bringing STI rates under control – particularly in remote Aboriginal communities – should remain a national priority until they are at least comparable to the rest of the Australian population.

Finally, ongoing efforts to improve access to needle and syringe programs and other harm reduction programs are required to reduce HIV notifications caused through injecting drug use.

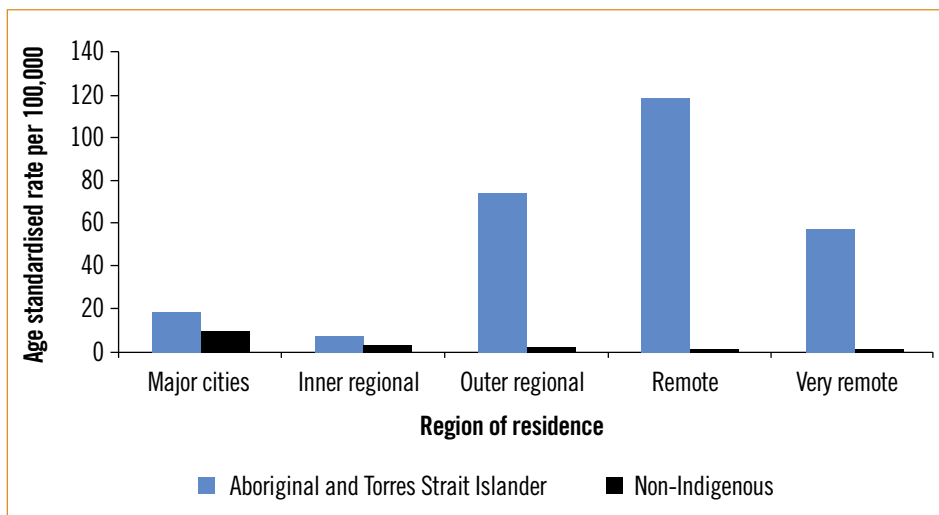
To achieve this, further efforts are required to ensure equitable access to:

- education and health promotion in school and teenage years
- effective and well-resourced clinical health service delivery, and
- effective prevention strategies such as needle and syringe programs (NSPs) and opioid substitution therapy (OST).

**For further information, see the *Bloodborne viral and sexually transmissible infections in Aboriginal & TSI people: Annual Surveillance Report 2015*, available at: <http://www.kirby.unsw.edu.au>**



**Figure 8:** Syphilis and infectious syphilis notification rates per 100,000, 2010–2014, by Aboriginal and Torres Strait Islander status. Source: Australian National Notifiable Disease Surveillance System; ABS Catalogues: 3101051-3101058; 3100D0003\_201212; 32380do001\_2011; Includes jurisdictions (ACT,NSW, NT, QLD, SA, Tas., Vic., WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses for each year.



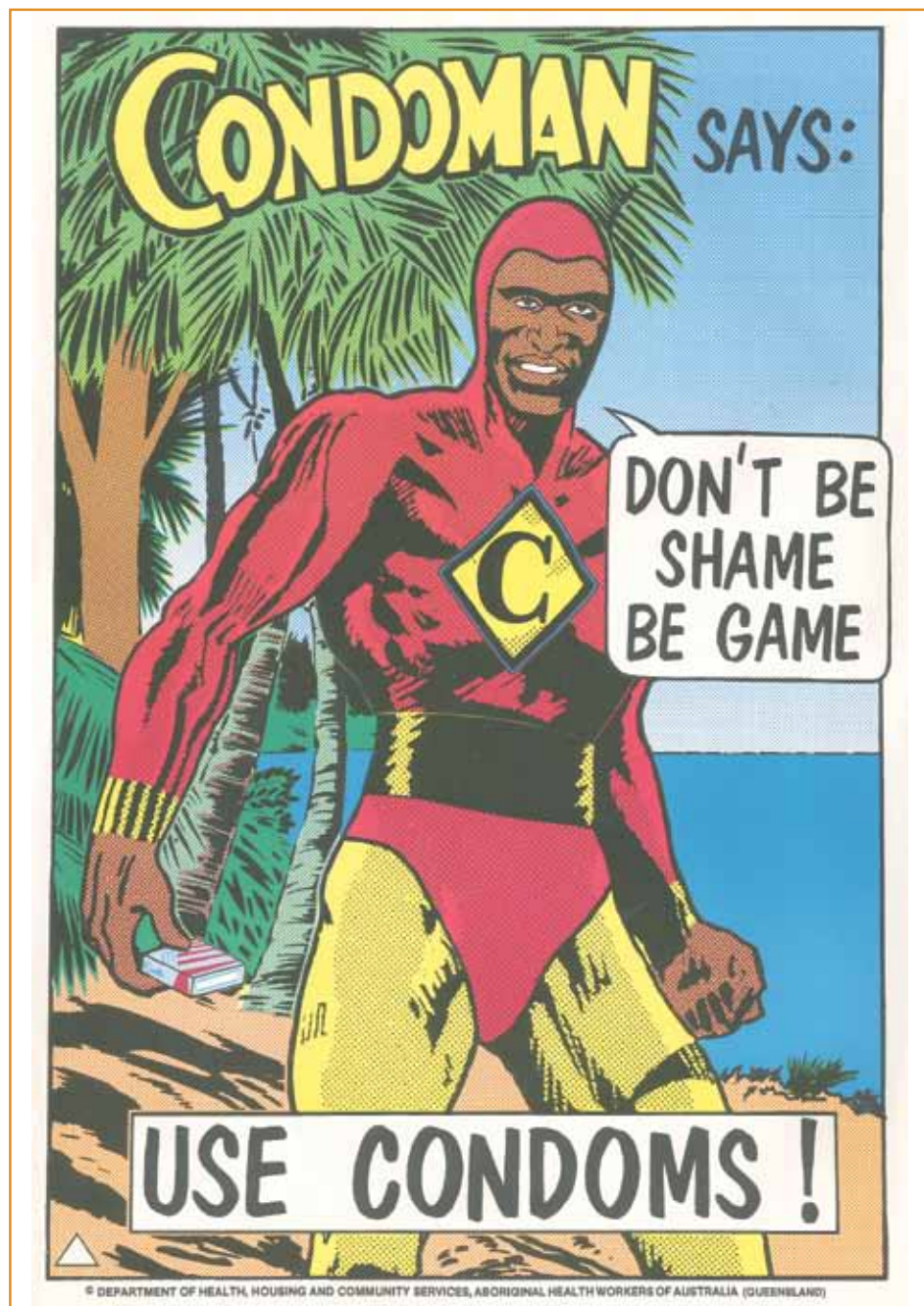
**Figure 9:** Infectious syphilis notification rate per 100,000, 2014, by Aboriginal and Torres Strait Islander status and area of residence. Source: Australian National Notifiable Disease Surveillance System; ABS Catalogues: 3101051-3101058; 3100D0003\_201212; 1270055006\_CG\_POSTCODE\_2012\_RA\_2011; ABS SuperTable 2011 Census; 32380do001\_2011; Includes jurisdictions (ACT,NSW, NT, QLD, SA, Tas., Vic., WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses for each year.

**Dr Marlene Kong is Program Head, Aboriginal and Torres Strait Islander Health Program at the Kirby Institute, UNSW Australia. Associate Professor James Ward is Head, Infectious Diseases Research Aboriginal and Torres Strait Islander Health at South Australian Health and Medical Research Institute (SAHMRI).**



# Health promotion retrospective

A snapshot of HIV health promotion campaigns produced by Aboriginal and Torres Strait Islander community members working in partnership with community and government health organisations.



Condoman says 'Don't be shame be game', use condoms (National Campaign Against AIDS – NACAIDS), designed by Michael Callaghan for Redback Graphix, 1987.



## Condoman

Condoman is one of Australia's longest running health promotion campaigns, having been first developed in 1987 by a group of Indigenous health workers in Townsville to promote and encourage condom use.

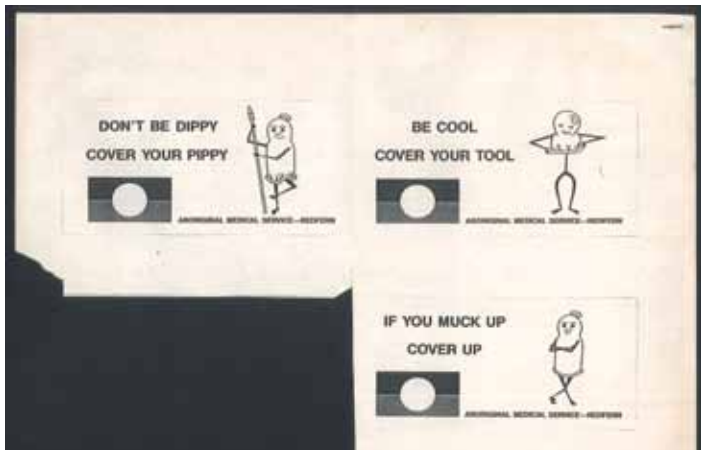
During the campaign, the action figure was referred to as the 'deadly protector of sexual health' and sprouted messages like don't be shame be game protect yourself and use frenchies/condoms. Aunty Gracelyn Smallwood remembers the first time she saw the Grim Reaper TV advertisements and quickly realised that the messages might not be seen or understood by Aboriginal or Torres Strait Islander people, so she secured a federal government grant to develop a campaign that would have impact on the population; and so, Condoman was born! He continues to live on and promote safe sex messages globally but importantly across Aboriginal and Torres Strait Islander communities. In 2009 the Condoman was reinvigorated and Lubelicious joined Condoman in continuing to promote safe sex.

At the 2011 International Society of STD Research Conference, Condoman was cited as one of the top 100 sexual health messages developed globally.

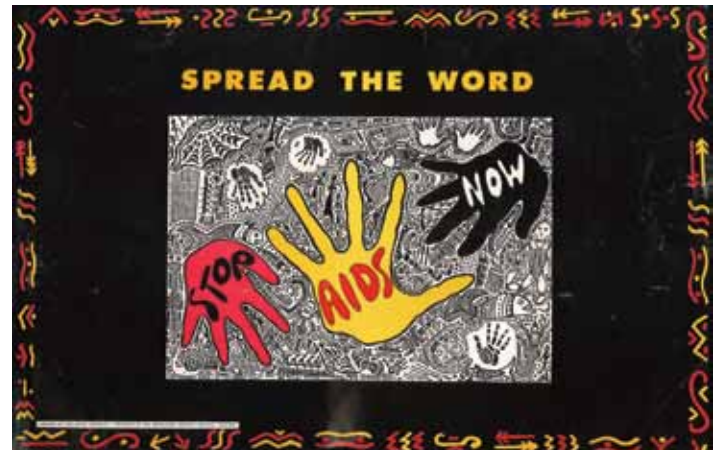
Archival posters appearing on pages 23–26 are provided courtesy of the Australian Lesbian and Gay Archives (ALGA). The posters are captioned to the extent of the information available, if you have additional details please contact the Australian Lesbian and Gay Archives: [mail@alga.org.au](mailto:mail@alga.org.au)



# Health promotion retrospective



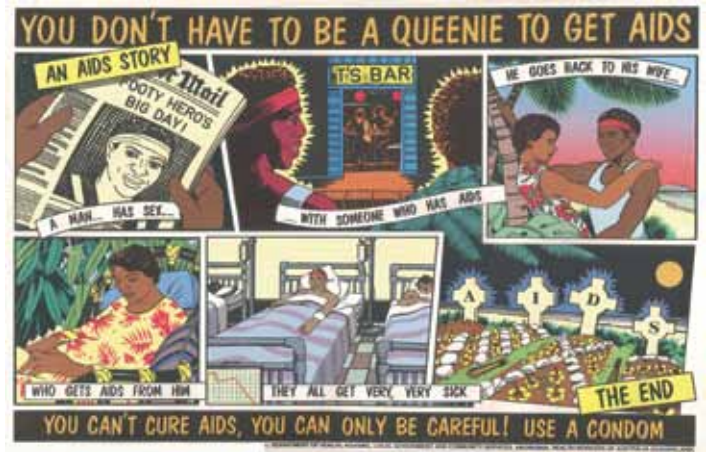
Don't be dippy, cover your pippy, etc. (Aboriginal Medical Service, Redfern, NSW), unidentified designer, c.1987.



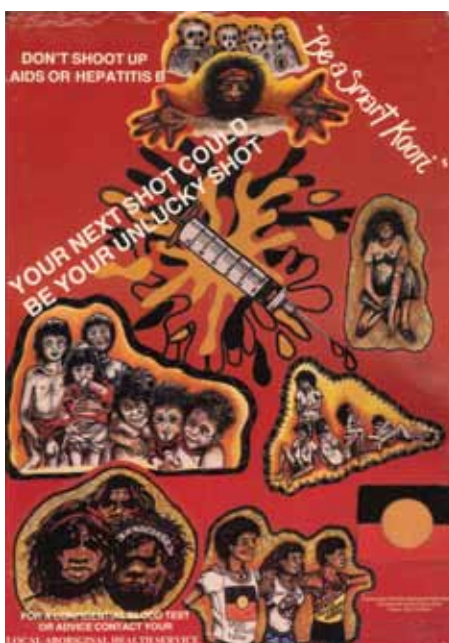
Stop AIDS Now, Spread the word (Aboriginal Medical Service, Redfern), designed and printed by Lou Davis Graphics, c.1988



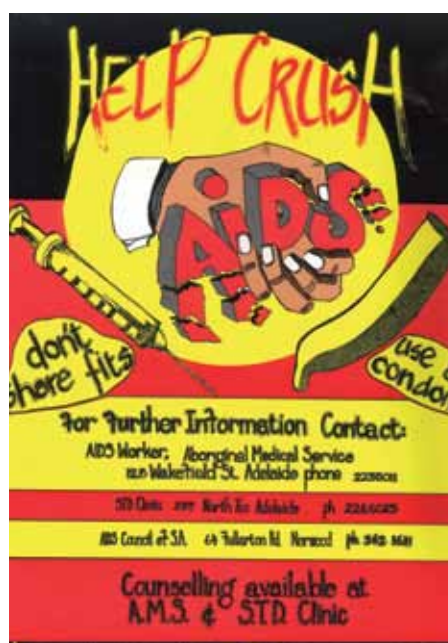
No condom – no way (National Campaign Against AIDS – NACAIDS), designed by Stephen Lees for Redback Graphix, 1988.



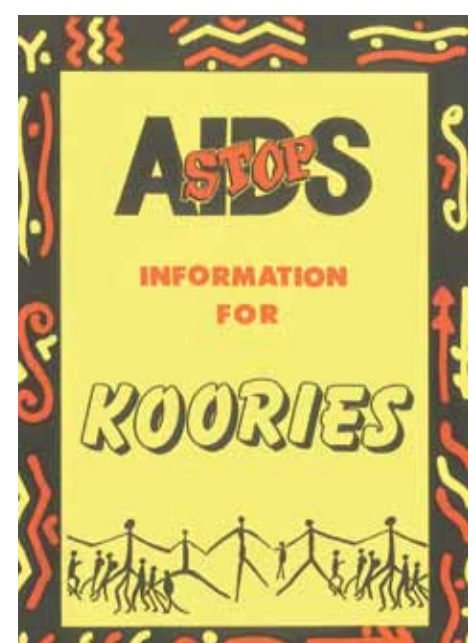
You don't have to be a queenie to get AIDS. (National Campaign Against AIDS – NACAIDS), designed by Stephen Lees for Redback Graphix, 1988.



Your next shot could be your unlucky shot. (Victorian Aboriginal Health Service), unidentified designer, c.1980s.

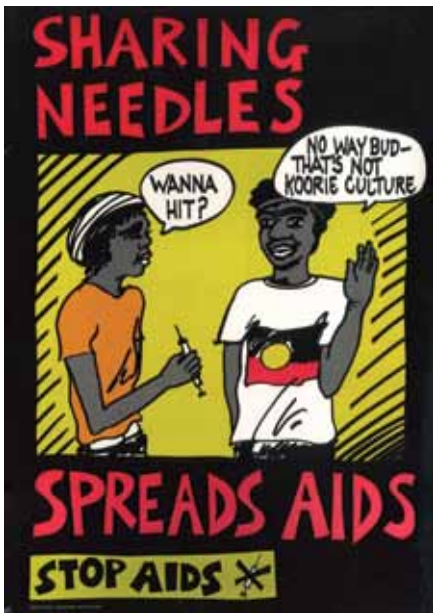


Help crush AIDS, (Aboriginal Medical Service, Adelaide), unidentified designer, c.1980s.



Stop AIDS, information for Koories, (Aboriginal Medical Service, Redfern, NSW), unidentified designer, 1987.

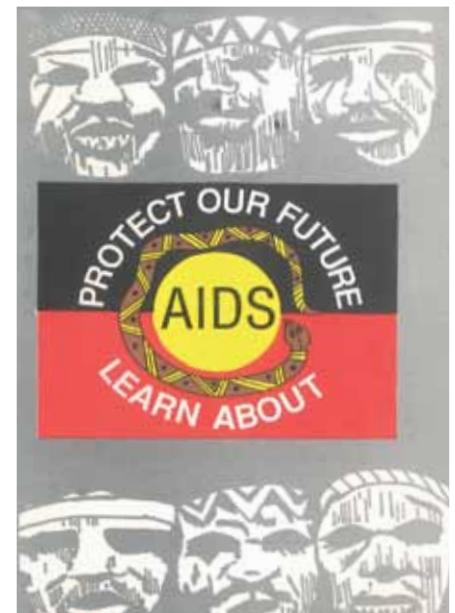




Sharing needles spreads AIDS – Stop AIDS, (North Coast Aboriginal Health Team), unidentified designer, c.1980s.



Care don't share – Stop AIDS (Aboriginal Medical Service, Redfern), designed and printed by Lou Davis Graphics, c.1988.



Protect our future, learn about AIDS, by Joanne Dwyer. (Victorian Aboriginal Health Service), c.1988.



Use a condom stay at ease, spread the word not the disease, (Aboriginal Medical Service Co-operative Ltd, Redfern), designed and printed by Lou Davis Graphics, c.1988.



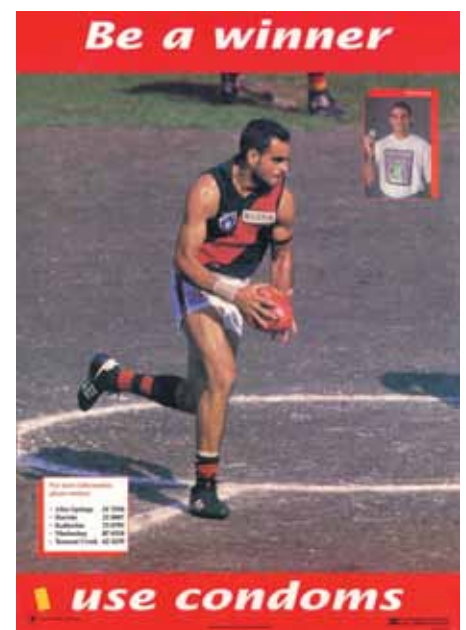
Love your lover have no other, (unidentified publisher), designed by Laura, c.1990s.



The knockout AIDS test today, (Streetwise Comics), designed by Dean Dobson and Joseph Banks, c.1993.



Don't be a fool, cover your tool! (Streetwise Comics), designed by Frank Coleman, Ray Merritt, Stephen Eatts, Adrian Dixon, Vernon Chillie, Chris Bates and Joey Wallace, c.1993.



Be a winner, use a condom, (NT Dept of Health and Community Services, Darwin), unidentified photographer, c.1995.



# Health promotion retrospective



Our future is in our hands, pick up knowledge, not HIV. (Indigenous Project, Queensland AIDS Council), unidentified designer, c.1990s.



Be my darling-darling – Use condoms! (Kimberley Aboriginal Medical Services Council), designed by Jimmy Pike, c.1990s.



When you take your pick, pick the right trick (Aboriginal Health Service, Adelaide), unidentified designer, c.1990s.



Education about AIDS – Every body's business, (Department of Health, Housing, Local Government and Community Services), artwork by Zine Saunders, 1993.



Don't put our people at risk with AIDS = AIDS ungkuntja wiyangu wantima nganampa anangu tjuta, (TAFE School of Aboriginal Education and the S.A. Department of Correctional Services), designed by Harry Power, printed at the C.T.I. Nunga Printshop by M. Stewart, S. Rankine, L. Carter, M. Taylor and A. Weetra, c.1990s.

See more images from the health promotion retrospective in *HIV Australia* online: [bit.ly/A-TSI-HPretro](http://bit.ly/A-TSI-HPretro)





The 'We're Family Too!' poster was endorsed by the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Australian National Council on AIDS, hepatitis C and Related Diseases (ANCAHRD). AFAO, 2000.



Proud to be Black, Proud to be Gay, AFAO poster series, 2009.



AFAO's Sistergirls Say campaign (2004) was a national peer-based poster and postcard campaign developed to promote positive self-esteem and sexual health among Indigenous sistergirl and transgender communities.



AFAO's Better To Know campaign (2012) includes a range of collateral and an interactive website ([www.bettertoknow.org.au](http://www.bettertoknow.org.au)) providing information on HIV and sexually transmissible infections, tailored to 'men's business' and 'women's business', a partner notification service, a testing reminder service and information about clinics and services split by state and territory.



'KUDJAK' is a Darwin (Larrakia) Aboriginal term for 'sex'. This t-shirt was produced for a youth sexual health workshop for Indigenous youth, held in collaboration with Danila Dilba and the Northern Territory AIDS and Hepatitis Council (NTAHC) in 2012.



Black Comedy star, Steven Oliver, fronts 'Take Blaktion', a campaign empowering Aboriginal young people to make informed decisions about sexual health. The NSW STI Programs Unit and the Aboriginal Health and Medical Research Council of NSW (AH&MRC), 2015.



'Our Destiny', a national Aboriginal and Torres Strait Islander HIV prevention, testing and treatment campaign. Anwernekenhe National HIV Alliance (ANA) and AFAO, 2013.



# Responding to HIV among Aboriginal and Torres Strait Islander people in the Northern Territory

By David Aanundsen

## Introduction

Although the AIDS pandemic reached Australia in 1984, it was not until a decade later that funding was allocated for Aboriginal and Torres Strait Islander programs at AIDS Councils, and Aboriginal responses to HIV began being led around Australia.

In Alice Springs in 1994, a non-Aboriginal man and Alice Springs resident, Phil Walcott, and Aboriginal man, John Cross (deceased), collaborated to secure Commonwealth funding and were involved in coordinating the first National Aboriginal, Torres Strait Islander Gay Men and Transgender Sexual Health Conference, held at Hamilton Downs.

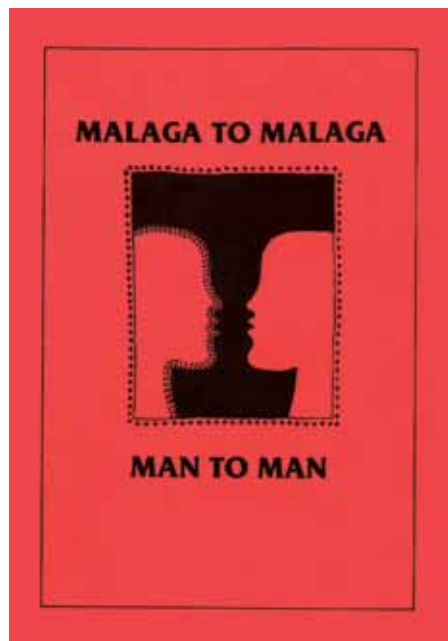
The Anwernekenhe conference set precedents through a series of recommendations for responding to the needs of Aboriginal and Torres Strait Islander gay men and transgender people, not only in the area of HIV/AIDS but also regarding broader sexual health and mental health needs. In 2015, Arnwernekenhe 6 is celebrating 21 years, and returned to Alice Springs to host its sixth conference.

The Northern Territory AIDS and Hepatitis Council (NTAHC) currently participates in the Anwernekenhe National HIV Alliance with membership on the Board; NTAHC participated in the Anwernekenhe conference, along with other representatives from HIV organisations across Australia.

## Paving the way: the Malaga to Malaga report

Initially, addressing HIV among Aboriginal people<sup>1</sup> in the Northern Territory (NT) – particularly among gay men and other men who have sex with men – was difficult, as there was little research or information available on the needs and concerns of these populations during the 1990s.

Gary Lee, a Larrakia man involved in the first Anwernekenhe conference as an NT representative in 1994, went on to



Cover image from Gary Lee's seminal report *Malaga to Malaga*, assessing the HIV needs of Aboriginal gay men and other men who have sex with men in Darwin.

address this dearth of knowledge. Gary first became involved with the NT AIDS Council in 1995 through his employment at Danila Dilba Aboriginal Medical Service, when his position was placed in the AIDS Council as an outreach worker.

Gary's brief was to work with Aboriginal people who identified as gay, bisexual, transgender or who used injecting drugs. It was at this time that Gary started work on gathering evidence to support the needs of Aboriginal people in relation to HIV/AIDS. His groundbreaking 1996 report, *Malaga to Malaga* ('Man to Man'), examined issues faced by the Aboriginal gay male community in Darwin and assessed the priority HIV/AIDS needs of this population.<sup>2</sup>

The recommendations of the report helped create a roadmap that sought to 'inform and lead to future planning, design, and delivery of more appropriate and informed education programs'<sup>3</sup>. Gary's achievements also helped in initiating the implementation of the Northern Territory AIDS Council's service delivery program for these target populations. Gary continued his research, and contributed

a number of other publications on Aboriginal gay men's and transgender populations.<sup>4</sup>

In 2015, NTAHC recognised Gary's outstanding contributions to the objects of the Northern Territory AIDS and Hepatitis Council by awarding him a Lifetime Membership Award.

## NTAHC's Aboriginal Sexual Health (ASH) program

NTAHC has been providing services across the NT since the late 80s, and in 2016 will celebrate its 30th year of incorporation. In 2003, the organisation changed its name from the NT AIDS Council to the Northern Territory AIDS and Hepatitis Council (NTAHC), to reflect a broadening of its scope to include hepatitis alongside HIV/AIDS.

During its history, NTAHC has provided services to people with blood borne viruses (BBVs), working predominantly with gay men, sex workers, people who use injecting drugs and Aboriginal and Torres Strait Islander people.

The NTAHC ASH program operates from Darwin and Alice Springs, and is staffed by Darren Braun, Aboriginal Sexual Health Promotion Officer and David Aanundsen, Aboriginal Sexual Health Coordinator. The ASH program has a long history of involvement in HIV support and awareness with direct client support. The ASH program also participates in conferences such as Anwernekenhe, hosts sistergirl retreats, develops Aboriginal-specific resources, and holds community stalls and education sessions to raise awareness about HIV, hepatitis and sexual health among Aboriginal people in the Northern Territory.

The bark painting, *If you Love Me, Love Me Safely* by Marrynula Mununggurr was commissioned by NTAHC in 2000. The painting uses a simple graphic style that shows 'the right way' and 'the sad way' (safe and unsafe sex). Posters and prints of the artwork were produced for use by





*If you Love Me, Love Me Safely* by Marrynula Mununggurr, commissioned by NTAHC in 2000.



Campaign produced by Sisters and Brothers NT and NTAHC promoting acceptance and support for gender diversity.

health workers in the field to educate Aboriginal people about using condoms to prevent HIV and hepatitis.

This is an extraordinarily explicit piece of work produced from within a culture that holds taboos about references to sexual practice. The bark painting refers to serious contemporary health issues faced by Aboriginal communities and to initiatives that have been taken by various health organisations in the Northern Territory to address these conditions. The painting also refers to issues of displacement and loss of access to traditional lands.

The original bark painting was sold to raise funds for the Council's Aboriginal and Torres Strait Islander AIDS and Hepatitis awareness project. In 2013, ASHM used the print as the official artwork for its Sexual Health and HIV Conferences in Darwin. In recognition of that, Marrynula Mununggurr reproduced a limited edition print in pastel colours.

### Transgender (sistergirl and brotherboy) support in the Northern Territory

The first Anwernekenhe conference was originally promoted as a gay men's forum, however, several sistergirls attended the first conference and sistergirl issues were also embraced, and the Anwernekenhe National HIV Alliance (ANA) now includes transgender representation. Transgender representation was endorsed

at the conference 'to give credibility to their orientation and lifestyle with reference to sexual health needs'<sup>5</sup>. NTAHC has been involved in supporting the needs of the Aboriginal transgender communities and has been holding sistergirl retreats over a number of years. Accessing services across the Northern Territory has often been difficult for sistergirls, and some have to travel long distances from remote or regional areas to urban areas to access services. Often there are no services to meet the specific sexual health needs sistergirls interstate, which necessitates travel to access support; many sistergirls end up leaving the NT for this reason.

The most recent annual sistergirl retreats were held in 2012 at Kakadu and in 2013 at the Mary River Wildness Retreat. In 2013, the event was renamed the Aboriginal and Torres Strait Islander Health Retreat and made available to all Aboriginal and Torres Strait Islander people who identify as sistergirl, brotherboy or LGBTI (lesbian, gay, bisexual, transgender, intersex) in the NT.

During the retreats, which occurred over a two-day period, information was delivered on HIV and sexual health and on accessing services in remote communities, with community members coming from all over the NT to participate.

Since then, NTAHC has determined that it can better support communities

of sistergirls and brotherboys through the dissemination of health promotion messaging, and has worked in partnership with the advocacy and support group Sisters & Brothers NT, to produce a range of culturally appropriate and relevant resources. This change in approach enables us greater reach into these communities.

### Aboriginal campaigns, promotions and safe sex resources

The NTAHC ASH program has continued to play a role in developing a range of Aboriginal-specific campaigns, health promotion and safe sex resources. More recently, the Live Deadly Stronger and Longer Ask For A Test campaign has been successful, with NTAHC collaborating with Congress Aboriginal Medical Service and Clinic 34.

Although the NT has some of the highest rates of sexually transmitted infections (STIs) in the country, testing rates among Aboriginal people remain low. Where testing is occurring, it is often not inclusive of BBV screening. NTAHC's 'Ask for a Test' campaign was produced and distributed throughout the NT to promote awareness about risk behaviours and to encourage Aboriginal people to access HIV, hepatitis and sexual health testing if they think they are at risk.

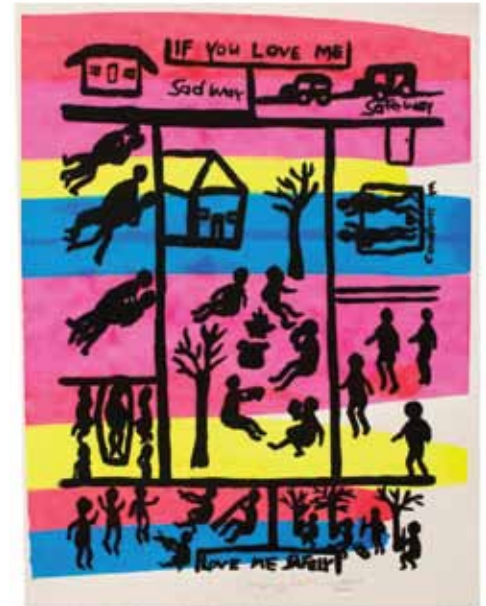
'Love Me Proper Way' condom packs have also been developed and are regularly



NTAHC's sista girl and LGBTI retreat poster, 2012.



NTAHC's 'Ask For A Test' campaign addresses low levels of BBV and sexual health awareness and literacy among Aboriginal communities.



*If you Love Me, Love Me Safely* by Marraynula Mununggurr, limited edition reprint, 2013.

supplied through NTAHC community stalls, Aboriginal community events and from the NTAHC offices. The packs include red, black and yellow condoms as well as lube sachets.

Distance is often a barrier to accessing sexual health services and information throughout the NT, so the ASH program launched an online social media presence through a Facebook page called 'Deadly Pride' (<https://www.facebook.com/DeadlyPride>), which is a page to share information on Aboriginal LGBTI issues and sexual health.

### Present and future concerns responding to the needs of Aboriginal and Torres Strait Islander people on HIV in the Northern Territory

Over the past year there has been a significant increase in syphilis in the NT, including notifications of congenital syphilis, which is of great concern. People with STIs are also at greater risk of acquiring HIV.

Aboriginal people make up thirty percent of the population of the Northern Territory, with a large percentage living in remote communities. Many of these people are living in extremely impoverished conditions, with poor access to health, housing, education and transport. Health clinics are often

over-burdened, under staffed and under resourced, and struggle to manage the acute care needs of the community, so sexual health and BBV screening often takes a back seat. Access to condoms and safe sex products is reliant upon people accessing the clinic, which can often be stigmatising and shameful.

Apart from community education delivered by NTAHC, in the Northern Territory there is very little information about BBVs and STIs reaching Aboriginal communities, or even the general population. With high rates of STIs and a disproportionate number of cases of viral hepatitis in the NT among Aboriginal communities, this leaves communities vulnerable to a potential HIV epidemic – underlining the urgent need to address STIs and BBVs among this population.

Scientific advances in preventing and treating HIV have provided the knowledge and the means to reduce new infections. New testing technologies are creating opportunities to significantly improve testing accessibility that can contribute to reducing transmission of STIs and BBVs; however, outside of urban settings, it is quite another situation. For many Aboriginal people living in remote regions, there is no internet access and it is difficult to stay up to date about new testing technologies, or to access information about STIs and BBVs.

Funding constraints are another issue to consider in getting STI and BBV information disseminated across the NT.

How do we continue to do this work with possible funding cuts? Despite these concerns, NTAHC remains optimistic in its approach. We do this work through ongoing relationships with remote communities, a strong social media presence and a commitment to developing culturally appropriate resources. A new HIV resource will also be launched this year. It is the first in a series with further resources being developed around hepatitis B and C, STIs and safe injecting.

### References

- 1 In this article, use of the term Aboriginal is inclusive of Torres Strait Islander peoples.
- 2 ACOCA closed in late 2002, and a program in Alice Springs was started by the Northern Territory AIDS and Hepatitis Council in 2003.
- 3 Lee, G. (1996). *Malaga to Malaga: Man to Man*. Danila Dilba Biluru Butji Binnilutlum Medical Service Aboriginal Corporation and Northern Territory AIDS Council, Darwin.
- 4 Hodge, D. (2015). Rationale for the nomination of Garry Lee for the NTAHC Lifetime Membership Award. Presentation to the NTAHC Board, Darwin, August 2015.
- 5 *ibid.*

David Aanundsen is Aboriginal Sexual Health Coordinator at NTAHC.



# ***Ngalawi Djardi* ('Sit and Yarn'): strengthening connections and sharing knowledge – the history of ACON's health retreat for Aboriginal people Living with HIV**

By ACON Aboriginal Project team

The ACON Aboriginal project provides a range of activities and services designed to be culturally appropriate for the Aboriginal and Torres Strait Islander gay, lesbian, bisexual, and transgender community. This includes an annual positive retreat program, where Aboriginal and Torres Strait Islander people living with HIV can engage in culturally appropriate respite, relaxation and recreational activities, social support, and professional support.

To adequately explain the *Ngalawi Djardi* ('Sit and Yarn') retreat, it is important to understand ACON's way of working. ACON works from a human rights perspective – good health flows from the achievement of human rights including education, social justice and equity, as outlined in the World Health Organization's 1986 Ottawa Charter for Health Promotion. ACON therefore uses a strengths-based community development approach to health promotion. That is, rather than being a service organisation addressing 'deficits' in the community, ACON instead recognises community resilience and strengths, and works to facilitate communities to strengthen connections, identify relevant issues, and take action to implement strategies for improving health and wellbeing. As communities access evidence-based knowledge, capacity for self-advocacy increases and this enhances the capacity and effectiveness of the whole community.

ACON's annual *Ngalawi Djardi* retreat for Aboriginal people<sup>1</sup> living with HIV is an important example of a strengths-based community development approach to health promotion. The retreat is sustained and continually improved by and for Aboriginal people living with HIV, building on decades of previous work.

To place the retreat within this context, an understanding of the history from which it came is essential. In the 1980s, HIV hit Australia hard in Sydney and a period of death, grieving and confusion about causes, effects and prevention was felt by the whole community. Many community leaders and potential leaders were lost. Recognising the need to come together to develop a nationwide strategy relevant to our people, Aboriginal people successfully pushed for the first Anwernekenhe conference, which took place in 1994 at Hamilton Downs, Mpartwe (Alice Springs) on Arrernte country.

Anwernekenhe provided a gathering ground to coalesce aims and strategies for Aboriginal and Torres Strait Islander action on HIV. People returned to their home states and lobbied their local HIV organisations to implement HIV responses that took account of our specific needs and community contexts. Thus, in 1998, ACON formalised its work with Aboriginal people by establishing a dedicated project team staffed by peers – Aboriginal people from the groups most at risk or affected by HIV. From its beginning, ACON's Aboriginal Project worked to hold regular gatherings for our people living with HIV, which gradually evolved into the current annual retreat model.

Our model aligns with the *Toronto Charter: Indigenous Peoples' Action Plan on HIV/AIDS*, which sets out recommendations about conducting HIV work with Indigenous peoples. The charter, launched in 2006 at the International Indigenous Peoples' Satellite during the 16th International AIDS Conference, articulates and formalises the same principles that ACON uses to guide its work: acknowledging Indigenous peoples' shared experiences relating to the AIDS epidemic; the impacts of the changing face of the epidemic on Indigenous communities; and appropriate ways of delivering health promotion that respects the rights of Aboriginal and Torres Strait Islander people.

A key principle within the charter that is central to our approach is 'nothing about us without us,' which means Aboriginal people – particularly those living with HIV – must be consulted and involved in all aspects of our HIV-related health promotion work, taking into account Indigenous models of holistic health, including cultural, social and spiritual as well as physical and mental health. The retreat, therefore, incorporates activities that address all of these aspects to provide a program that is culturally safe, informed and accessible.

One example of the way the retreat continually evolves in response to participant feedback is the name itself. A desire for the retreat to have a distinct and meaningful name led to ACON facilitating a community call-out for potential names in 2012. Online voting was conducted and *Ngalawi Djardi*, which means 'sit and yarn' in the Sydney basin's Darug language, was the winning name.

*Ngalawi Djardi* continues to provide a platform for Aboriginal people living in NSW to contribute to the development of HIV policy that affects us at national and international level. For example, in 2014 participants discussed the issues that would be taken by delegates to the 2014 International Indigenous Pre-conference on HIV and AIDS, and from there to the 20th International AIDS Conference.

In 2015, the retreat was held just prior to Anwernekenhe 6 to enable retreat participants to have a say on issues taken to the conference even if they were not able to attend.

In addition to being responsive to Indigenous ways of being, the epidemiological need for an Indigenous-specific retreat for NSW residents is clear. In 2013, around a third of all Aboriginal people newly diagnosed with HIV were in NSW.<sup>2</sup>

The population rate of HIV diagnosis in the Aboriginal and Torres Strait Islander communities, in 2014, was 1.6 times higher than for non-Indigenous people. As with the non-Indigenous community, gay and other homosexually active men within Aboriginal and Torres Strait Islander communities bear the greatest burden of HIV. Latest data (2010–2014) show that almost 60% of Aboriginal people diagnosed with HIV were men who have sex with men, compared to 80% of diagnoses in the non-Indigenous population.<sup>3</sup>

There are however some unique differences in the way HIV impacts our communities:

- Women make up a greater proportion of people diagnosed with HIV – but the rate of transmission via heterosexual sex is equivalent to the general population.<sup>4</sup>
- In the non-Indigenous population, sharing injecting equipment accounts for 3% of new HIV diagnoses. In the Aboriginal and Torres Strait Islander population it accounts for 16%.<sup>5</sup>

- Indigenous men in Australia are more likely than non-Indigenous Australian men to report unprotected anal intercourse with casual partners, and more than twice as likely to report injecting drug use.<sup>6</sup>

Therefore, for cultural reasons of inclusion and for epidemiological reasons of addressing the diversity of those affected, the retreat is open to women, men, sisters/girls and brotherboys, of any sexual identity.

Development of each year's *Ngalawi Djardi* retreat is based on these principles and is informed by participant feedback. The retreats aim to increase the health and well-being of Aboriginal people and Torres Strait Islander people living with HIV by providing respite and relaxation, opportunities to connect and share stories with other HIV positive people and opportunities to celebrate and share culture, art and good yarns and by access to professional workers.

The retreats also serve important population-based health objectives. Aboriginal people in NSW suffer a greater burden of ill health than other populations. The impacts of colonisation and dispossession, poverty, poor nutrition, low educational outcomes, the geographic remoteness of some communities, and other factors – including high mobility, lower health literacy, and the concept of 'shame' around discussing sexual health – contribute significantly to underlying poor health status. The retreats bring together members of an otherwise hard-to-reach population to promote health in a culturally accessible manner.

The retreats also create opportunities to gauge responses to existing health promotion initiatives and open up discussions that will help to inform work that targets the broader Aboriginal population.

At the retreats, attendees' life experiences are recognised and valued. The people best placed to talk about the impacts of HIV are those living with HIV. Attendees return to their home communities able to pass on up-to-date information on HIV testing, treatment, prevention, campaigns and services.

The majority of attendees are attached to the gay community or are homosexually active. These men can become role models and distribute information to their peers.



The retreat provides opportunities for participants to hear about, and access other platforms for capacity development and peer-based education. Examples include ACON workshops such as Genesis, and the Positive Leadership Development Institute (PLDI) program and the Positive Speakers Bureau.

*Ngalawi Djardi* is a successful program that meets community needs. ACON is committed to continuing to support the right to self-determination of Aboriginal people living with HIV and to providing this retreat for as long as Aboriginal people are living with HIV in NSW.

## References

- 1 In recognition of NSW as Aboriginal land and consistent with NSW Health guidelines informed by consultation with Aboriginal communities, this article refers to 'Aboriginal people' or 'Aboriginal gay and homosexually active men' but is inclusive of Torres Strait Islander peoples.
- 2 The Kirby Institute. (2014). *Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander people: surveillance and evaluation report 2014*. The Kirby Institute, UNSW Australia, Sydney.
- 3 Between 2010–2014, 50% of Aboriginal people diagnosed with HIV were men who have sex with men (MSM), with a further 8% of cases diagnosed among Aboriginal MSM who also engage in injecting drug use. See: The Kirby Institute. (2015). *Bloodborne viral and sexually transmissible infections in Aboriginal and Torres Strait Islander people: Surveillance and Evaluation Report 2015*. The Kirby Institute, UNSW Australia, Sydney.
- 4 *ibid.*
- 5 *ibid.*
- 6 The Kirby Institute. (2014). *op. cit.*

Read more from ACON's Aboriginal project in *HIV Australia* online: <http://bit.ly/Explr01>



# The last weekend in October: my *Ngalawi Djardi*

By Stephen Morgan

My name is Steve Morgan, I am a Gamillaroi man from North West NSW – and like many of my fellow Aboriginal and Torres Strait Islander LGBTI community – I left my country town to gravitate toward the gay scene in Sydney to seek inclusion and to feel a part of a community.

As a newly diagnosed HIV-positive Aboriginal man, I have personally felt alone and isolated. I had all these fears around what my diagnosis meant for me into the future, how my HIV status would affect my physical, psychological and emotional wellbeing, and how it would impact upon my family. I had a personal fear for my mob and what this all meant for them.

I sought advice and information around HIV; I was aware of ACON and the work they did in the community so they seemed to be the obvious place to start. I was referred to the Genesis workshop, but at that time the program was in its infancy and I felt it didn't offer the kind of support that I needed.

I was encouraged to attend the *Ngalawi Djardi* Health retreat that ACON runs for the Aboriginal and Torres Strait Islander HIV-positive community. I was told to



Stephen Morgan at Anwernekenhe 6, November 2015.

come along and give it a go, and if I didn't get anything out of it then obviously I wouldn't have to return.

To my surprise, what I found was a safe space for me to share my concerns, a place of support that offered a culturally appropriate component that made me feel included. *Ngalawi Djardi* provided an outlet for me and others to share what it was like to live with HIV and I gained more awareness and knowledge of HIV and the impacts upon community.

Attending the *Ngalawi Djardi* retreat was extremely important, in that it gave me the strength to firstly have that conversation with my family, and secondly, it provided the support mechanism I needed to reduce the fear I was consumed with.

The *Ngalawi Djardi* retreat provided a therapeutic benefit in that it showed that I was not alone, there was a shared life experience that I could tap into and hearing others speak of their journey reassured me that there was support available and that I would be ok.

Now the last weekend in October is a special time for me and others. It marks a coming together of HIV-positive Aboriginal people<sup>1</sup> in NSW; it provides a safe space to reconnect and gives the newcomer a sense of belonging. I highly recommend it to my brothers and sisters.

**Stephen Morgan is Aboriginal Health Promotion Officer at ACON.**

## Endnote

- 1 In recognition of NSW as Aboriginal land and consistent with NSW Health guidelines informed by consultation with Aboriginal communities, this article refers to 'Aboriginal people' or 'Aboriginal gay and homosexually active men' but is inclusive of Torres Strait Islander peoples.

## *HIV Australia* online features additional content not available in print

The online edition includes additional articles from ACON and Queensland Positive People (QPP), as well as expanded image galleries from Anwernekenhe 6 and our health promotion retrospective.

Read *HIV Australia* online at: [bit.ly/HIV-Australia](http://bit.ly/HIV-Australia)



# 2Spirits: providing a multi-generational, culturally competent approach to health promotion for Aboriginal and Torres Strait Islander communities

By Brett Mooney and Phillip Sariago

A key outcome from the inaugural Anwernekenhe conference was the recommendation to establish an Aboriginal and Torres Strait Islander HIV and AIDS Project in each AIDS Council in Australia. This resulted in the formation of the National Working Party of Aboriginal and Torres Strait Islander gay men, sisters/girls and people living with HIV. The job of the working party was to help forge a response to the HIV epidemic threatening Indigenous communities in Australia, which set the foundations for an ongoing community-driven program to address HIV among Aboriginal and Torres Strait Islander communities in Queensland.

The Queensland AIDS Council formed its 2Spirits program in 1996. 2Spirits currently consists of a small team of Health Promotion Officers – Nikki Hill and Arone Meeks based in Cairns, Phillip Sariago and Brett Mooney in Brisbane and Manager/Executive Director, Michael Scott. The program adopts a ‘whole of community’ approach for providing HIV, sexually transmissible infections (STI) and blood borne virus (BBV) health education.

Queensland is traditionally the home of many Aboriginal and Torres Strait Islander peoples. The state has the largest combined population of both cultures in Australia, uniquely setting us apart from all other states and territories. 2Spirits is seen by peers as specialists in our approach in developing and maintaining a cultural presence in health-based community engagement, to empower individuals to make informed choices about their sexual health.

Over 19 years of service delivery, 2Spirits’ specialist program has provided culturally appropriate sexual health promotion projects in Queensland, and national campaigns such as Condoman. It is the only program in Australia providing a cultural workforce development project that focuses on the health and wellbeing of Indigenous gay men and sisters/girls. In



Tony Coburn, Brett Mooney, Wilo Muwadda, Shannon Jackson, Earl Roses, Brendan Leishman at Condoman relaunch, Brisbane, 2009.

addition, our program addresses stigma, discrimination and associated violence that is often aimed at Aboriginal and Torres Strait Islander gay men and sisters/girls within communities.

## Health promotion projects

Our program provides education across the life span. The 2Spirits team works closely with young people across Aboriginal and Torres Strait Islander communities in Queensland, delivering a six week sexual health program at the Aboriginal Centre for the Performing Arts (ACPA) in Brisbane to first year student cohort. The program has had a positive impact with students, expanding their knowledge on how they view and make better choices around their sexual health. Building on this relationship, 2Spirits have employed students from ACPA to raise community awareness focusing on sexual health and regular testing by portraying Condoman, Lubelicious and other STI characters at community events in NAIDOC Week and World AIDS Day.

At the opposite end of this age spectrum, 2Spirits works with Aboriginal and Torres Strait Islander Elders, through Elder’s Forums. As custodians of Indigenous cultures, it is imperative that Elders are actively involved in the planning, promotion, implementation and evaluation of programs and not simply included. For

this reason, 2Spirits has involved Elders as key stakeholders throughout its history of service delivery.

In 2013, 2Spirits conducted an Elder’s Project with community Elders drawn from communities as far apart as Yarrabah in Far North Queensland, down the East coast of Queensland to Stradbroke Island. The aim of the project was to develop health promotion through the voices of our Indigenous Elders educating communities about sexual health, support, tolerance, acceptance and the importance of family regardless of sexuality.

Creative approaches are intrinsic to the work of 2Spirits. To increase community awareness in far north Queensland communities, art workshops provide individuals another form of learning and expression relating to identity, sexuality, acceptance, inclusion, diversity, respect and sexual health. The artwork produced from these workshops is used to develop relatable individual and community oriented health promotion resources and campaigns.

A partnership with the Brisbane Indigenous Media Association (BIMA), developed a range of radio skits featuring super heroes Condoman and Lubelicious to educate and normalise sensitive topics about sexual health, people living with HIV (PLHIV) and



treatments and removing stigma and shame, acknowledging men's and women's business. Adopting radio to get into homes to educate communities on sexual health in ways never before utilised, the skits are promoted through airways in the south east, central and northern parts of Queensland as well as in Tasmania.

### Cultural competence training

2Spirits have identified a significant need for cultural competence training across Queensland. The program invests resources and time within each community, building workforce capacity with organisations that provide services for gay men and sistergirl and brotherboy communities within those communities, as well as providing specialised cultural awareness and workforce development for organisations to engage effectively with these populations.

2Spirits has developed partnerships with key community organisations through conducting service provider forums. One such forum, held in Rockhampton, promoted sexual health and awareness of an Aboriginal and Torres Strait Islander gay men and sistergirls target group in Central Queensland. 2Spirits partnered with Queensland Health in Rockhampton to assist in setting up the first Central Queensland Youth Interagency Sexual and Reproductive Health Forum in 2014 for service providers to create linkages and strategies to reduce rates of HIV and STIs.

The 2Spirits team works collaboratively with Indigenous and mainstream services to ensure that communities have a greater understanding of key areas of health promotion, delivered in an appropriate way. 2Spirits has collaborated with Hepatitis Queensland and the Torres Strait Islander community to produce a series of hepatitis brochures in the Creole language (the primary binding language spoken throughout the Torres Straits). 2Spirits revamped Condoman, the longest running sexual health campaign in Queensland to include the Torres Strait colours into his costume, making the super hero inclusive of two traditional cultures in Queensland.

### Mental health and wellbeing

Many Aboriginal and Torres Strait Islander gay men and sistergirls routinely face a variety of challenges related to

their sexuality. This can lead to a range of mental health problems, many of which are related to the issue of acceptance and homophobia from the wider Indigenous and non-Indigenous communities. Other issues of concern relate specifically to service provision – issues such as access, inclusiveness, confidentiality and cultural sensitivity by service providers.

Medical professionals require development of their ability to appropriately address the unique health needs of gay men, sistergirls, brotherboys and lesbians. Widespread neglect from past governments has carried through to current generations, leading to poor health that has added additional strain on health services that are ill equipped in their service models for Aboriginal and Torres Strait Islander people.

The effects of past government policies that led to the removal of Aboriginal and Torres Strait Islander children from their families continues to present severe consequences for social and emotional wellbeing; poor mental health leads to unconventional forms of coping mechanisms that place Indigenous people at risk of further negative health implications.

Intergenerational trauma and grief continues to cause Aboriginal and Torres Strait Islander people many health and social challenges, forcing 2Spirits to adopt strategic approaches in our holistic service delivery to ensure our clients receive appropriate health care to meet their needs.

### Looking to the future: addressing gaps in funding, knowledge and awareness

Funding has been challenging for 2Spirits, particularly in an environment where there are increasing rates of STIs and HIV among Aboriginal and Torres Strait Islander gay men and other men who have sex with men (MSM), and sistergirls in Queensland.

Currently 2Spirits consists of three full- and one half-time health promotion officers that provide service to the whole mainland state of Queensland and support 17 Islands of the Torres Strait across urban, rural and remote settings. To be more effective in our current workforce capacity, additional funding would be beneficial to develop more culturally

appropriate HIV and STI prevention programs and health promotion in areas of high population density for our target group, the far north Queensland regions. Uniquely, 2Spirits modifies its health promotion strategies to allow for growth and empowerment of communities to be a part of effective, culturally appropriate and sustainable sexual health outcomes.

2Spirits has identified gaps in knowledge and awareness with health professionals that provide services to gay men, MSM and sistergirls who are identified as most at risk target groups in several national and state Strategies including the *Third National Sexually Transmissible Infections Strategy 2010–2013*, *Fourth National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2014–2017*, *National Aboriginal Torres Strait Islander Peoples Drug Strategy 2014–2019*, *National Aboriginal and Torres Strait Islander suicide prevention strategy* and the *Queensland Mental Health, Drug and Alcohol Strategic Plan*.

Homophobia and acceptance of homosexuality continues to be a problem in Australia for Aboriginal and Torres Strait Islander gay men, sistergirls, brotherboys, lesbians and the wider LGBT community. The 2Spirits program will continue to work with health professionals and communities to enable Aboriginal and Torres Strait Islander gay men and sistergirls (in particular) to take control of their health and improve their quality of life.

Increased funding for more community education and promotion is vital to strengthen 2Spirits' current workforce capacity for our Queensland wide brief, and to extend our service delivery to address mental health, drug and alcohol use, suicide and lesbian health for this at risk target group that continues to be presented with discrimination and inequities within service provision, legislation and society.

### Reference

- 1 Lavarch, L. (1997). *Bringing Them Home Report*. Commonwealth of Australia, Canberra

**Brett Mooney and Phillip Sariago are Health Promotion Officers, 2Spirits Program/Queensland AIDS Council.**

# Improving treatment outcomes for HIV-positive Aboriginal and Torres Strait Islander people at Cairns Sexual Health using the treatment cascade as a model

By Morgan Dempsey, Mary Elliott, Carla Gorton, Joanne Leamy, Sara Yeganeh and Karly Scott

This article reflects the work of the multidisciplinary team of Aboriginal and Torres Strait Islander health workers, doctors, pharmacists, psychologists and nurses at Cairns Sexual Health to improve the treatment outcomes for HIV-positive Aboriginal and Torres Strait Islander people. Our service uses the treatment cascade as a model to gauge our success in improving health outcomes for people living with HIV, as it describes the stages of health care that people living with HIV pass through, from diagnosis through to viral suppression.

Our clinic is fortunate to have an onsite pharmacy with an HIV Pharmacist and Pharmacy Assistant. Cairns Sexual Health usually sees 12–13 new cases of HIV each year, with 1–2 cases per year among Aboriginal and/or Torres Strait Islander people. However, in July 2014, our service began to see a spike in the number of new cases of HIV among Aboriginal and/or Torres Strait Islander men who have sex with men (MSM). This was the catalyst that drove our team to question whether we really knew our epidemic.

As a team, we believed that our service adequately met the needs of our clients in terms of engagement to service, initiation and adherence to antiretroviral (ART) treatment with achieved undetectable viral load (VL). In 2014, our Intern Pharmacist conducted an audit (with approval from Cairns Hospital and Health Service Ethics Committee) of Aboriginal and Torres Strait Islander people living with HIV, who were attending Cairns Sexual Health. A key question asked in the audit was, 'Once clients reach undetectable, do they stay there?'

The audit identified 25 HIV-positive people who identified as Aboriginal and/or Torres Strait Islander. Of this cohort, 22 people were receiving ART, 16 were undetectable and 20 were engaged in care.

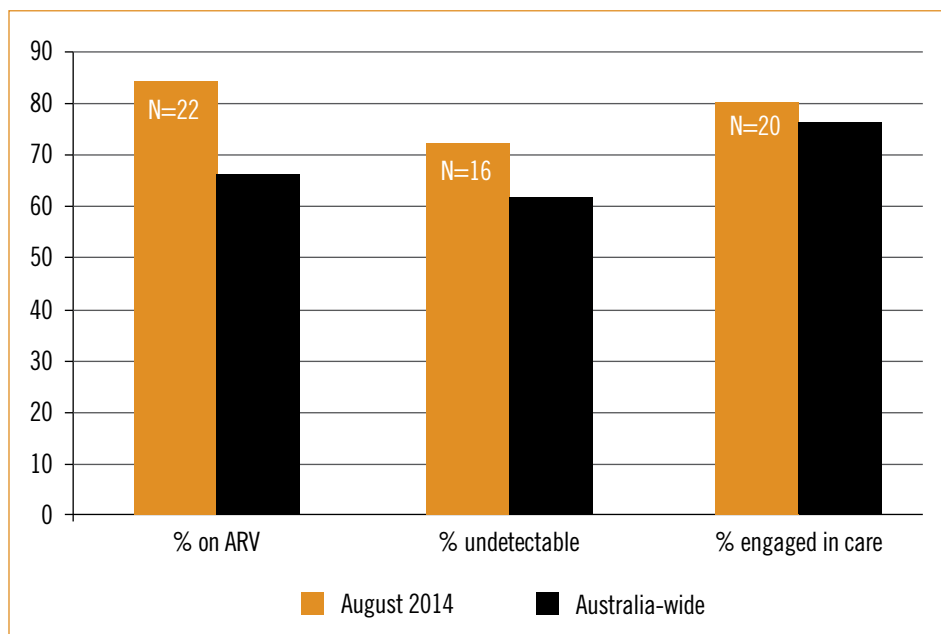


Figure 1: Comparison of data on Aboriginal or Torres Strait Islander people living with HIV in North Queensland (August 2014) and people living with HIV Australia-wide (2014).<sup>1</sup>

Figure 1 compares our August 2014 figures on engagement, treatment and viral load status against Australia-wide data on people living with HIV.

By the end of 2014, Cairns Sexual Health had 15 new cases of HIV, with 6 (40%) identifying as Aboriginal and/or Torres Strait Islander men who have sex with men (MSM). The audit also found that of these new cases, 50% were diagnosed by GP services and 33% by Aboriginal or Torres Strait Islander health care services.

## Assessing the treatment cascade

We were interested to know how this cohort of people measured on the HIV treatment cascade. The cascade is often presented as linear, where a person receives a positive HIV test result; is linked to care; begins antiretroviral treatment; maintains engagement with care and ART; and achieves viral suppression.<sup>2</sup> However Sprague and Simon (2014)<sup>3</sup> describe how people move in and out of the treatment

cascade, rather than progress in a linear manner (see Figure 2, overleaf).

Although we perceived our service to engage this group well, the audit highlighted that this cohort appear to move in and out of the treatment cascade depending on what is happening in their lives at any given time. We found that individuals may or may not engage in HIV care following diagnosis; may or may not begin ART; may or may not remain on ART; may disengage; and may re-engage when they become ill or are hospitalised. Many reasons for this movement seem to be based around the social determinants of health such as culture, income, housing, education, place of birth, social exclusion, and the wider forces and systems that impact on daily life.<sup>4</sup>

We observed that the barriers<sup>5</sup> or causes of leaks<sup>6</sup> from the treatment cascade included: the clinic entrance; lack of transport; homelessness; lack of family awareness, no support; HIV literacy; recreational drug use;



family and cultural responsibilities; hidden nature of taking ART; stigma; lack of finance; work; and new diagnosis.

Clients also stated:

- 'I just wanted to run away'
- 'Drugs were awful'
- 'Am sleeping on couches'
- 'I need to get some food now'
- 'I live in 2 houses'
- 'I need to feed the children'
- 'I have a Pharmacy bill'
- 'I live with other people'
- 'I cannot tell my family'
- 'Family work at health service'.

When we looked at our service, we identified our own barriers, including:

- 'But why won't he just take his pills?'
- 'Disruption' to clinic flow
- 'He is my client'
- Inflexibility of service model
- For missed appointments, it becomes a fine line between following up or stalking!
- Lack of funding to culturally appropriate NGOs
- Lack of social infrastructure
- Need for social workers.

Our service continued to monitor how this small group of HIV-positive people move in and out of the treatment cascade over a 12-month period (see Figure 3). As at September 2015, our service has 29 Aboriginal and/or Torres Strait Islander HIV-positive clients, 27 of whom are male (all MSM) and 2 female.

Over the 12 months we have developed our knowledge and insight into barriers affecting engagement of Aboriginal and/or Torres Strait Islanders with HIV care. As a team we have actively used this insight to put in place enablers to health care access, which has resulted in a dramatic shift from 80% to 100% of the cohort being engaged in care; with currently 89% on ART and 69% undetectable.

In our experience, the enablers for engaging and maintaining Aboriginal and Torres Strait Islander HIV-positive people in care are many and varied, and we needed to remain flexible.

Aboriginal and Torres Strait Islander health workers have been central to facilitating engagement, access to services, education and support, as they work in a holistic way. Cultural protocols, men's and women's business, stigma, shame

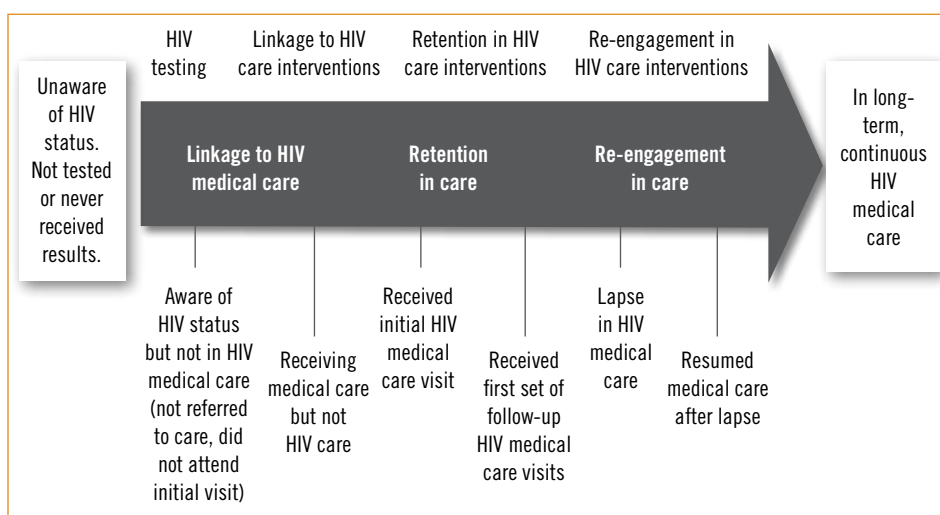


Figure 2: Treatment Cascade (Sprague and Simon 2014)<sup>7</sup>

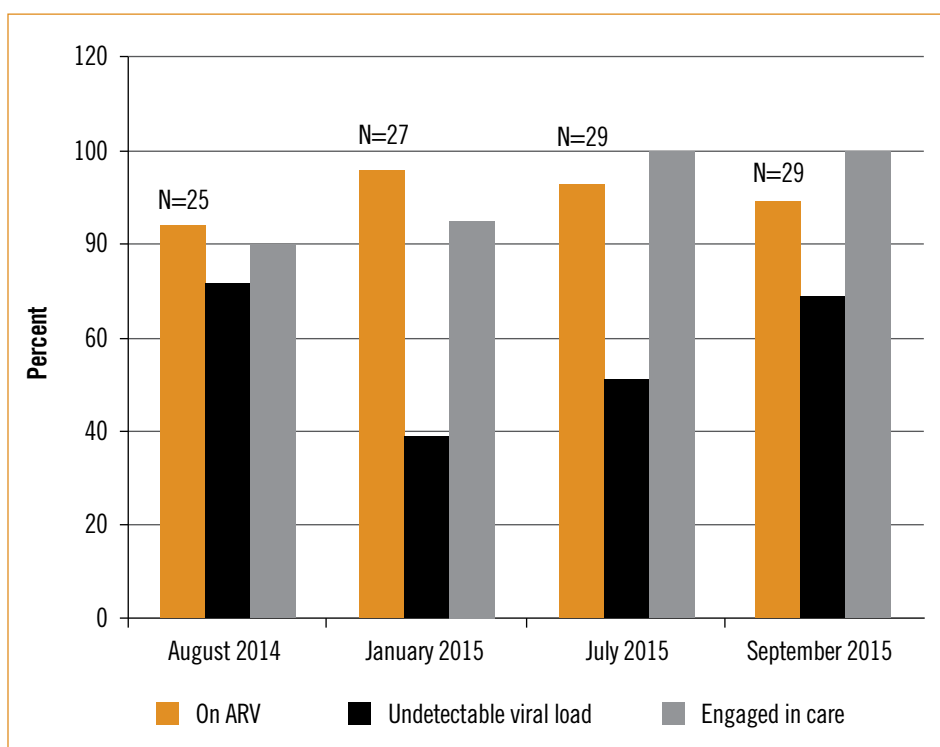


Figure 3: Treatment cascade at Cairns Sexual Health over time, from 2014–2015.

and being ostracised in community are contributing factors as to why Aboriginal and Torres Strait Islander people are reluctant to engage in health services for HIV treatment. While the Aboriginal and Torres Strait Islander health workers followed cultural protocols, we sometimes found that young men preferred to engage with an older female health worker.

Some examples of enablers to health care access within our service:

- Rearranging the waiting room so that the chairs face the window rather than the entrance, improving anonymity and reducing shame
- Utilising the staff back door entrance rather than bringing reticent people

through the front door, which is labelled 'Sexual Health'

- Improving links between hospital and clinic, with clinic staff and HIV Pharmacist visiting people when they are admitted to hospital. Service includes providing information about the Sexual Health Clinic, and providing support for people newly diagnosed around HIV and ART
- Establishing a pharmacy fee waiver for ART to clients with financial problems
- Providing increased flexibility of scheduling appointments
- Provision of transport to and from appointments

- As a service, we became better at ‘expecting the unexpected’
- All members of the multidisciplinary team are crucial to providing holistic care
- We provide information about different staff, which allows clients to choose who they would like to see. This has allowed clients to develop positive relationships with particular staff
- SMS was used to engage clients initially, and often we could have SMS conversations prior to meeting the client. This gave people a chance to get to know us slowly and engage on their terms. It also meant we could ascertain when it suits them for us to call so they don’t use their own phone credit. SMS is also used to remind clients of their appointments.
- We spent time supporting non-clinical staff to understand why this group of people needed extra support.

### Key learning outcomes

This work has improved our knowledge of the HIV treatment cascade and of factors that enable clients to maintain engagement in care. It is important to

note that people do not maintain an undetectable viral load forever.

Care by a multidisciplinary team of Aboriginal and Torres Strait Islander health workers – including pharmacists, nurses, psychologists, and doctors – is essential. Each team member needs to get to know the whole person, rather than focusing only on HIV. Clinical services also need to provide flexible models of care. Our experience illustrates the importance of dismantling barriers as they arise, in order to keep people engaged in care.

It seemed to us that those requiring most support to engage in care, take antiretroviral treatment and remain in care were diagnosed within the last two years. This is useful information for services to be aware of when caring for Aboriginal and Torres Strait Islander people who are newly diagnosed with HIV.

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## It's all about relationships: a story from the frontline about the ups and downs of managing HIV in remote Australia

By Marisa Gilles

Since 1994, a small cohort (approximately 20 people) of heterosexual HIV-positive clients in remote Australia has been managed by a team of health care providers. The philosophy of this service is not only to deliver high quality clinical care, but to have a culturally appropriate, holistic approach, with strong social and practical support.

The initial team consisted of two Aboriginal health officers – one male and one female. Both were well respected in their community and had strong personal links with the clients – to the extent that the female health officer was known by them as ‘aunty’. Other members of the team were a nurse, a doctor, a case manager and a secretary. The latter did not limit her role to purely administrative duties, but also responded to unexpected requests for transport, accommodation and companionship when required.

Clinical care of the cohort is shared between this local team and a specialist immunology team based at a tertiary hospital. In the early days, while relationships were being formed (both with the clients and also with the

local team), these specialists visited the community three times a year. Not only did this mean that the clients saw a familiar face if they had to go to the hospital for specialist treatment, it also meant that the local team learnt about the latest treatments for managing HIV.

I have been involved in the care of these people since 1998; half of the original cohort, all diagnosed as HIV-positive between 1994 and 2002, are still alive and well.

That we have not been able to prevent every death in the original cohort saddens me, especially when I know that we had the tools to keep them alive. I still agonise about why I could not persuade some clients to take their medication. One in particular – a young girl who was infected at the tender age of 16 – found her diagnosis just too hard to absorb. Despite accompanying her to the tertiary hospital to support her to have lifesaving treatment, she rejected all care and died just after her 21st birthday. This tragic and unnecessary loss of a vibrant young life will stay with me forever.

I needed to know if our approach was working and how well we had performed

compared to other services looking after people living with HIV, so this year I carried out a review of the outcomes. I looked at parameters associated with successful delivery of the service – including survival, viral loads, CD4 counts, pregnancy outcomes, as well as reviewing the investment of time required to achieve these results.

Of the original cohort, all of those who have survived are still closely connected to the service and 93% are on antiretroviral treatment. Despite what might have been expected in a cohort of people with complex social situations, adherence with medication regimens has been good; 73% have undetectable HIV viral loads, 67% have CD4 counts greater than 500, and 87% have a CD4 count greater than 250.

There have been only two HIV-positive babies out of 24 pregnancies among the cohort; one of these babies was born before the status of the mother was known, preventing any antiretroviral prophylaxis during her antenatal period or at delivery. This audit demonstrated that, when such care is provided, excellent outcomes can be achieved.

But this is a story about people and relationships, not just percentages. As you might expect after all this time, these people have become more than just individuals living with HIV – they have become my friends. They all have my mobile telephone number and know that they can call me if they find themselves in situations that require urgent resolution.

For example, someone might need to fly to the city to be with a close relative who has been admitted to hospital, or they might need a hotel room for a night or two when their family is getting too much, or they might need to arrange special funding to buy a fridge, air conditioner or heater. At other times people have asked for a letter of support for housing issues or a reference for a job. And sometimes they just call to talk to someone they trust when they are frightened about what is happening to their bodies.

Back in 1994, it was felt that HIV-positive women should not have babies, as there was a high risk their children would be born with HIV and that mothers would die before their children had grown up. One woman, who was 'persuaded' to have

a tubal ligation after a miscarriage, wanted it reversed five years later when she was in a new relationship and successfully on treatment with an undetectable viral load. Normally this procedure would cost several thousand dollars, but the doctor looking after her advocated for the operation to be done free of charge. She now has a beautiful daughter in her life and is likely to live to see her get married and have children.

The majority of the time our contact with the clients is about their social needs or transport, not medical appointments. The demand on our services varies from individual to individual and from time to time – ranging from four or five face-to-face contacts a year, to almost daily contact when they need someone to support them through a difficult patch.

There is often confusion about what it means to deliver equal or equitable services. Far from providing the same care to all our clients, we deliver targeted, culturally secure services to a small cohort of Aboriginal people living with HIV. The results achieved have been good – indeed

they are comparable to results seen among non-Aboriginal people living with HIV.

The management and selection of antiretroviral medication has changed over time but our commitment to maintaining a close personal relationship with this cohort of clients has not. Although challenges to obtaining ideal outcomes persist, I firmly believe that our holistic service, characterised by developing and continuing relationships with the clients, is the reason we have complete engagement of our cohort and have achieved positive outcomes in 73% of cases.

This model of care, although labour intensive, delivers results similar or better than those seen internationally in hard-to-reach populations. It demonstrates that equal outcomes can be achieved when equitable services are provided in a culturally appropriate manner.

For me, despite the challenges and frustrations, working with these people has been an inspiring journey and an experience that I wouldn't have missed for the world.



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# Strengthening community capacity to maintain low levels of HIV among Aboriginal gay men and other men who have sex with men (MSM), sistergirls and brotherboys in South Australia

By Wills Logue

## Introduction

Indigenous people globally remain at higher risk of HIV and sexually transmissible infections (STIs) than non-Indigenous people. In Australia, gay and other men who have sex with men are disproportionately affected by HIV, and, as a result, HIV transmission among this population has been well researched; however, there is little known about HIV transmission among homosexually active Aboriginal and/or Torres Strait Islander (hereafter referred to as Aboriginal) men. Even less is known about how cultural factors specific to the Aboriginal population may influence the sexual behaviours of this population group.<sup>1</sup>

James Ward suggests that the stable HIV incidence experienced by Aboriginal people should be celebrated with optimistic caution.<sup>2</sup> He asserts that the success in keeping HIV prevalence low can be attributed to community capacity building and developing and delivering culturally appropriate health promotion messages. These include the Condoman campaign, which gained wide support across the Aboriginal community, by employing a sexual health message that was free from embarrassment and 'shame'.<sup>3</sup>

Since August 2015, SAMESH (South Australian Mobilisation and Empowerment for Sexual Health) has delivered a range of services in South Australia – including campaign development, counselling, peer support, workforce education, rapid HIV testing, and support for people living with HIV – and is committed to ongoing work with Aboriginal and Torres Strait Islander communities.

The previous Gay Men's Health program of the AIDS Council of South Australia (2013) partnered with the Aboriginal Health Council of South Australia and other key stakeholders to develop the

Respect Test campaign – an HIV and sexually transmissible infections (STI) testing campaign targeting Aboriginal South Australians, irrespective of their gender or sexuality. Respect Test was the first locally produced campaign in South Australia that saw stakeholders work in partnership and establish meaningful relationships with community members to co-develop and design a culturally appropriate health promotion campaign. The campaign received community endorsement in metropolitan and regional South Australian Aboriginal communities.

Gay Men's Health South Australia (GMHSA) – a program of Relationships Australia, South Australia (2013–June 2015) – recognised the role Aboriginal and Torres Strait Islander community members and community-based organisations such as the Moolagoo Mob could play in strengthening the profile of community identity in health promotion programs. A strong sense of community identity was central to the success of the Respect Test campaign in South Australia, which focused on raising community knowledge on issues regarding sexuality, HIV and STI transmission, and prevention strategies.

Community participation, the inclusion of Aboriginal sexual health workers in communities, and an inclusive policy and partnership approach are critical to ensure an escalated epidemic does not occur.<sup>4</sup> GMHSA recognised its failure to develop an ongoing relationship and partnership with Aboriginal gay men in South Australia; consequently, an invitation to establish a reference committee was extended to Aboriginal gay men, men who have sex with men (MSM), sistergirls and brotherboys, and community workers from the South Australian Aboriginal LGBTIQ (lesbian, gay, bisexual, transgender, intersex and queer) community. The committee's function was to provide expertise to

GMHSA; design and distribute a community survey to identify the gaps in services for gay men and men who have sex with men; ensure HIV education for Aboriginal people is culturally appropriate; and encourage the blood borne virus (BBV) and STI sector in South Australia to acknowledge the necessity for an Aboriginal, Gay Men, MSM, Sistergirl and Brotherboy Action Plan.

## Online survey

### Methodology

As part of the community consultation process, GMHSA has worked with a reference group of community members consisting of gay men, MSM, sistergirls, brotherboys and Aboriginal health workers to develop a survey using the online platform, Survey Monkey.

The survey was open for gay, MSM, sistergirls and brotherboys community responses from 15 June–26 July 2015, and was promoted through community health networks and online social networks including Facebook, Moolagoo Mob, Aboriginal Health Council SA, and various other regional networks and mainstream services. The results of the survey will assist in the future development of a culturally appropriate Health and Wellbeing Action Plan to address the needs of Aboriginal gay men and other men who have sex with men, sistergirls and brotherboys.

### Participants

Survey responses were received from 25 Aboriginal community members; 85% of respondents identified as Aboriginal and 15% as both Aboriginal and Torres Strait Islander. Participants were spread across all age groups, but the largest age group (41.7%) were people aged 25–40 years. Over half (59.1%) of the participants were female, 27% were male, 9% identified as sistergirl, and 5% identified as other.

### Sexuality and relationship status

Half of the participants identified as heterosexual, 27.3% as gay, 9.1% as lesbian, 9.1% as bisexual and one person as pansexual. Most (77.3%) participants were single, 9.1% were married and 9.1% have multiple partners. Most (68%) said they would like to have sex with males, 16% with females, 8% with transgender and 8% either with sistergirls or brotherboys.

### Where do they live?

The majority of the respondents (80%) were currently living in the city, and most had originally come from outside metropolitan areas (50% from rural areas, and 20% from remote areas). When asked about the reason to move to the city, the main reason was family (36%), followed by work (32%) and study (16%). Overall, 12% reported that they moved due to gender-related discrimination, and 8% reported sexuality-related discrimination/violence as a reason to move from a rural or remote location (see Figure 1).

### Access to sexual health services and the Gay Men's Health service in SA

Most (73.7%) respondents have access to sexual health services in South Australia. Others said they did not go to sexual health services for a range of reasons including: 'I don't know where to go', '[I] see the local GP instead' and 'There was no necessity'.

Two out of six gay men who had visited the Gay Men's Health Service reported that they have other alternative services in convenient places such as their GP, Clinic 275 or services operating in rural areas. Those participants who did not identify as gay thought that Gay Men's Health was a service only for the gay community. Therefore, a communication strategy would need to be developed around the service to attract potential clients who do not identify as gay but who are men who have sex with men, sistergirls or brotherboys.

### Services accessed at Gay Men's Health

Irrespective of whether they had attended the Gay Men's Health Service, we asked participants what services they would expect to receive at the Gay Men's Health Service. Around one-third (32%) said counselling, followed by HIV testing/STI screening (24%), sexual health workshops (20%), and health promotion campaign material (20%), as shown in Figure 2.

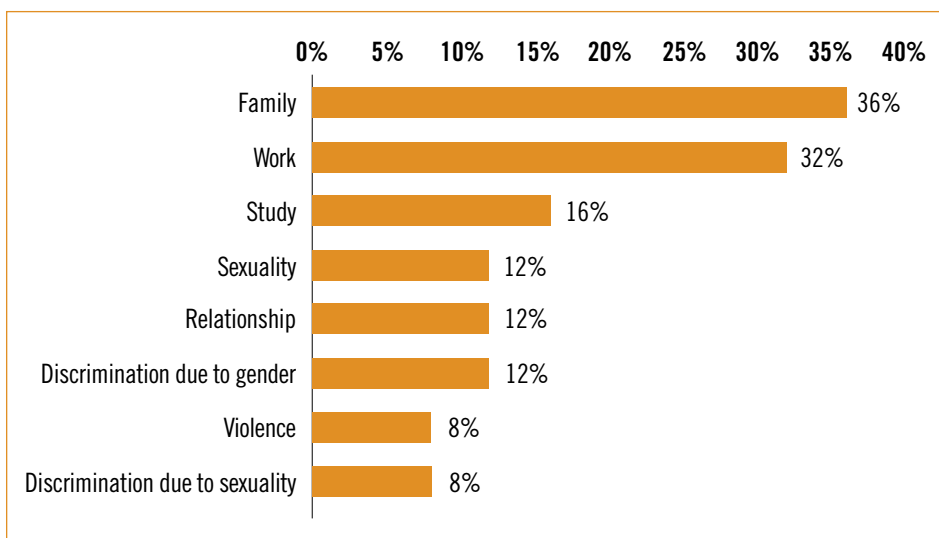


Figure 1: Reason to move to the city.

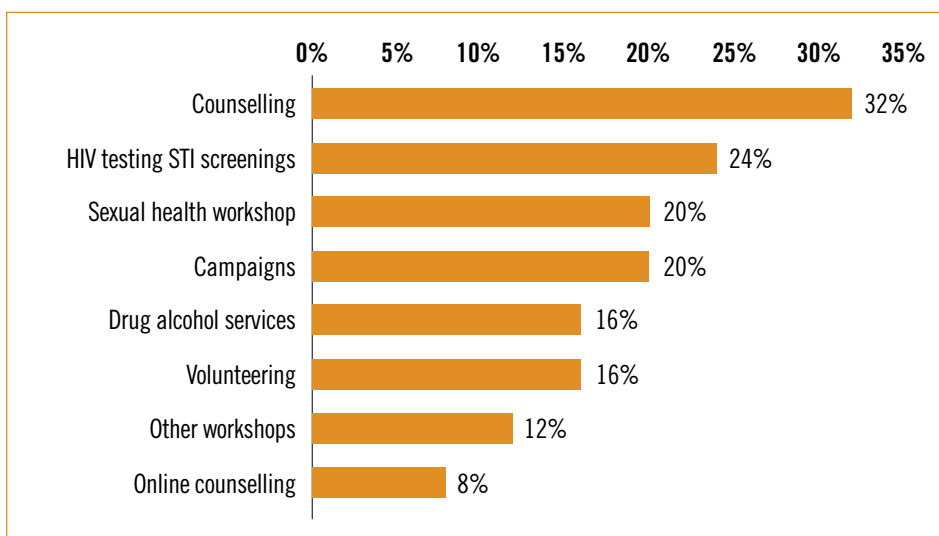


Figure 2: Expectations of service provision at Gay Men's Health Service.

### Barriers and availability of sexual health resources for Aboriginal and Torres Strait Islander communities

When we asked whether there are enough sexual health resources for Aboriginal and Torres Strait Islander gay men, men who have sex with men, sistergirls, and brotherboys, most participants (87%) stated 'No'. They also named the types of resources that they would like to access.

Some respondents said they would like to see more resources and promotional material that would broaden community engagement and build connections with the wider community, and increase community awareness about the problems faced by some Aboriginal people related to sexual identity and sexuality. Nine participants answered the question, calling for more resources to be developed, and more education opportunities for Aboriginal health organisations to explore

complex sexuality issues. This included social media/online information and campaigns and referrals relating to sexual health. The respondents also saw benefit in increasing community awareness through print media, such as pamphlets, brochures, posters, and booklets.

Most participants considered the main barriers to accessing sexual health resources as a lack of understanding within rural communities and remote health services about issues that affect Aboriginal gay men, men who have sex with men, sistergirls and brotherboys.

### STI check-up and HIV status

Most participants (89.5%) had received an STI check-up within the last year; 26% said they had accessed an STI check-up within the last six to twelve months, while 21% said they have had check-ups more recently, that is, within the last month to six months. Only one out of ten



respondents (10.5%) had never had an STI check-up.

10.5% of participants said they were HIV positive, and 21.1% said that they did not know or would prefer not to reveal their HIV status; the majority of respondents (68.4%) reported 'negative' HIV status (see Figure 3).

### Issues affecting Aboriginal and Torres Strait Islander gay men, MSM, sistergirl and brotherboys in South Australia

All participants were asked to name the three main issues affecting Aboriginal and Torres Strait Islander gay men, men who have sex with men, sistergirls and brotherboys in South Australia. Over half of respondents (56%) reported lack of acceptance by the wider community/family as the main issue, followed by lack of support/education about sexual health (28%), safety issues (20%) and the problem of accessing appropriate health and social services (12%) (see Figure 4).

Most of the respondents commented that they felt shame, due to a lack of acceptance by the wider community, and even from their families. Therefore, they considered that proper education and greater awareness about their complex sexual needs and sexuality-related issues was necessary among the wider Aboriginal and Torres Strait Islander communities.

### What did we learn?

The survey results demonstrate that despite stable rates of HIV among Aboriginal and Torres Strait people in South Australia, this population remains at increased risk from HIV and STIs. Ongoing community capacity building and education – including culturally appropriate health messages – would assist to narrow the gap in services for Aboriginal gay men, men who have sex with men, sistergirls and brotherboys, especially for those residing in rural and remote regions of Australia.

Campaigns addressing issues of 'shame', aimed at families within the wider Aboriginal and Torres Strait Islander community, would be highly beneficial in increasing community awareness relating to HIV and STI transmission and prevention strategies. Further targeted health promotion encouraging access to sexual health services would clearly result in an overall increase in testing rates and reduction in risk.

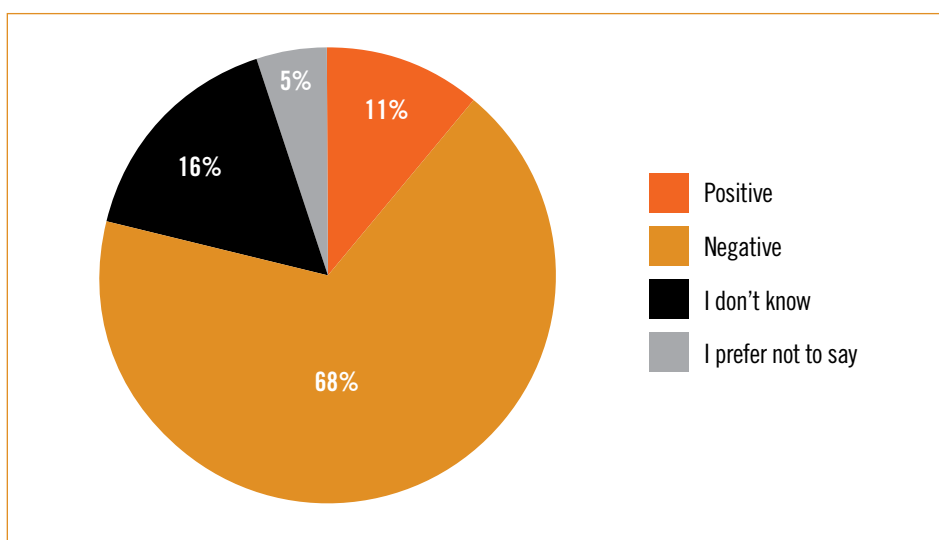


Figure 3: Self-reported HIV status.

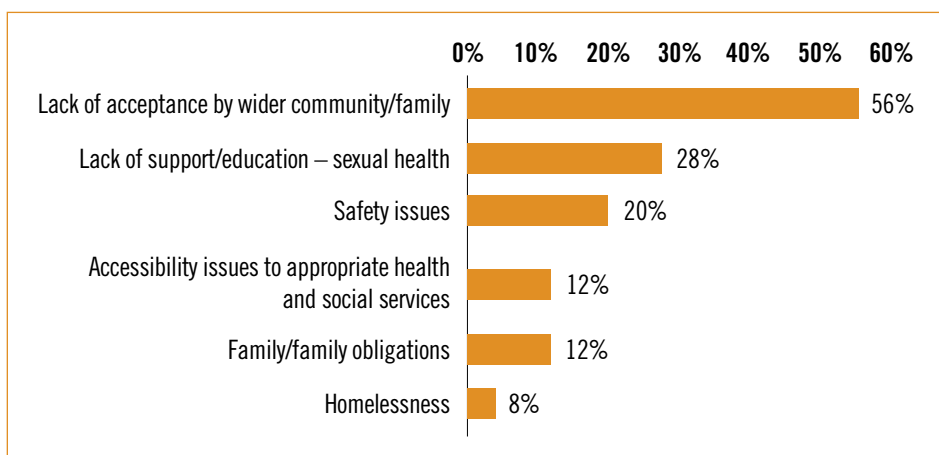


Figure 4: Three main issues affecting Aboriginal and Torres Strait Islander gay men, MSM, sistergirls and brotherboys in South Australia.

The survey overwhelmingly highlighted the overall lack of acceptance and the sense of belonging by the wider community and families which resulted in individuals feeling a sense of 'shame'. This frequently resulted in the need for counselling services. Individuals strongly believed that wider community education would result in a greater awareness about their complex sexual health needs and sexuality-related issues. The survey highlighted the need for development of various resources for use by rural and remote health services and community members.

In response to these findings, SAMEESH has reinstated the Aboriginal Gay Men's, MSM, Sistergirl and Brotherboy Reference Committee that was formerly positioned at GMHSA. SAMEESH has entered into a partnership with the Close the Gap team – a program of SHine SA – to recruit an Aboriginal gay man to further engage with the reference committee and

to develop a suite of culturally appropriate sexual health training packages for regional and rural Aboriginal health workers and community leaders.

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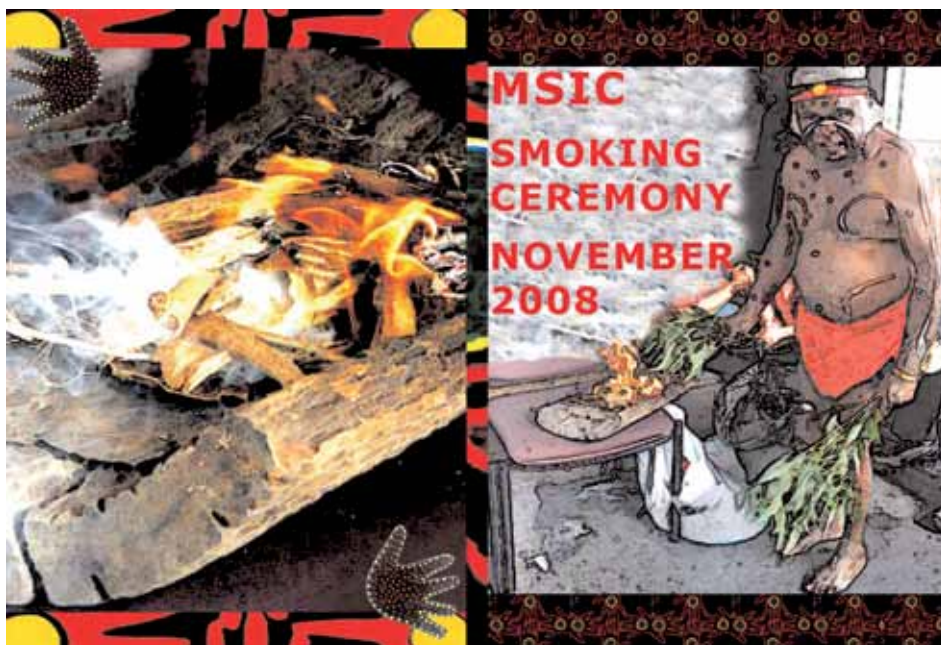
# 'This Way in the Right Direction': *Itha Mari* – The Aboriginal Health and Healing Group at the Kirketon Road Centre

By Christine Kerr and Rosie Gilliver

The Kirketon Road Centre (KRC) is a primary health care facility based in Sydney's Kings Cross, established in April 1987, as a result of a recommendation of the New South Wales Parliamentary Select Committee on Prostitution. KRC provides prevention, treatment and care for HIV/AIDS and other transmissible infections among 'at risk' young people, sex workers and people who inject drugs, as well as innovative outreach programs to youth services, strip-clubs and sex-parlours in the local area. In addition, the KRC conducts nightly mobile outreach to those living and/or working on the streets of East Sydney, Woolloomooloo and Darlinghurst.

Many of the clients engaging with HIV prevention services in these local inner-city settings identify as Aboriginal and/or Torres Strait Islander people. Indeed, in 2015, almost 10% of KRC's clinical work and 37% of the clients enrolled in its Opioid Substitution Treatment harm reduction program identified as Aboriginal, Torres Strait Islander or both. This compares favourably to the latest census data, which shows Aboriginal and Torres Strait Islanders make up only 1.3% of the local government area population.<sup>1</sup> Within this population group, there is a similar prevalence of HIV as the general population at KRC.<sup>2</sup> Additionally, 50% of KRC's services are provided to people with a history of injecting drug use, and of those, 50% are living with chronic hepatitis C.

Since its establishment, 10–15% of KRC's clients have identified as Aboriginal and/or Torres Strait Islander (hereafter referred to as Aboriginal people). In 1996, KRC undertook a needs analysis in acknowledgment of the specific health, social and cultural needs of this client group, the findings of which recommended the appointment of an Aboriginal Health Educator. Since then, KRC Aboriginal Health Project Officers have fulfilled an important health education and community outreach role, building links in the local Aboriginal community to increase access to KRC for HIV prevention, medical and psycho-social services.



Poster for Smoking Ceremony held at the Medically Supervised Injecting Centre (MSIC), November 2008.

In 2003, a further needs analysis was undertaken with Aboriginal clients accessing KRC to further identify specific needs of the community. It was apparent that while some Aboriginal clients were visiting KRC on a daily basis for the Opioid Substitution Treatment program, others were irregularly attending for drug and alcohol support and drop-in. As a group, the needs analysis identified that Aboriginal clients were reticent about accessing further services, especially sexual health services.

In 2004, the *Itha Mari* Aboriginal Health and Healing Group was established in response to clients' requests to establish an Aboriginal group that could meet regularly to voice and focus on their health needs and other concerns. *Itha Mari*, from the Barkindji language, meaning, 'this way in the right direction' was proposed by a Barkindji woman who attended the group, and was unanimously agreed on by all participants as a true reflection of their expressed goals.

*Itha Mari* supported Aboriginal clients who were experiencing challenges related to drug use, general medical and psycho-social health and wellbeing. Clients were encouraged to play an active role within *Itha Mari* so that KRC staff, in

collaboration with clients, could identify barriers, work together to dismantle them, and improve access to the service. The importance of *Itha Mari* lies in empowering clients to participate in decision making relating to their health outcomes, as well as in facilitating their reconnection to their countries, their cultures and their languages.

Since the program's conception, *Itha Mari* has included weekly luncheons with Aboriginal Elders and guest speakers, targeted health promotion activities, cultural excursions, literacy and art projects and, more recently, storytelling. These groups have all been very different, but all held common goals: promoting and encouraging confidence and self-esteem, sharing knowledge and experience, giving expression to individual needs, exploring feelings and preferred futures, reflecting on themselves and their communities, and rebuilding connections.

Throughout the duration of the program, there have been many collaborative community activities undertaken by *Itha Mari*, including the creation of a beautiful panel for the inaugural Aboriginal and Torres Strait Islander AIDS Memorial Quilt, participation in cultural field trips



and art sessions, the development of a literacy program in collaboration with Tranby Aboriginal College, contributions to the National Drug Strategy through Koori Radio<sup>3</sup> and community celebrations during NAIDOC Week – including the annual smoking ceremony and KRC Koori Film Festival. The specific health promotion activities coordinated by KRC for Koori clients have included women's and men's health groups, mental health awareness, sexual health and drug and alcohol focus groups, healthy liver discussions, harm minimisation and healthy relationships sessions.

Three significant cultural projects in which KRC clients have participated are described in greater detail below.

### Aboriginal and Torres Strait Islander AIDS Memorial Quilt

In 2004, *Itha Mari* clients were invited to create a panel that would become an integral part of the inaugural Aboriginal and Torres Strait Islander AIDS Memorial Quilt. The clients participated in this project with much respect and commitment and developed the design to:

*'... represent all of us, protected by the Rainbow Serpent whose eggs represent new life and rebirth. The boomerangs in the four corners of the panel represent the return of the spirits to the Rainbow Serpent's eggs. The smoke from the burning gum leaves is our spirit and our healing. It also represents those who have passed on. The coloured hands and feet represent our togetherness and together, we stand. The flag represents our proud nation. The willy-wagtail and the symbol of the AIDS virus represent the bad news AIDS brings. The central yellow sun represents a brand new day and hope. The river running across the panel represents our different paths and different tribes joined together. There is no beginning and there is no end to this river ... WE SURVIVE.'*<sup>4</sup>

KRC clients attended the inaugural unfolding of the quilt at La Perouse with great pride at being present to honour those for whom the quilt was created and for whom deep loss was felt.

### Literacy program

In 2007, Tranby Aboriginal College and KRC, partially funded by the Indigenous Coordination Council, delivered a Literacy program to KRC clients each fortnight over a period of ten months.

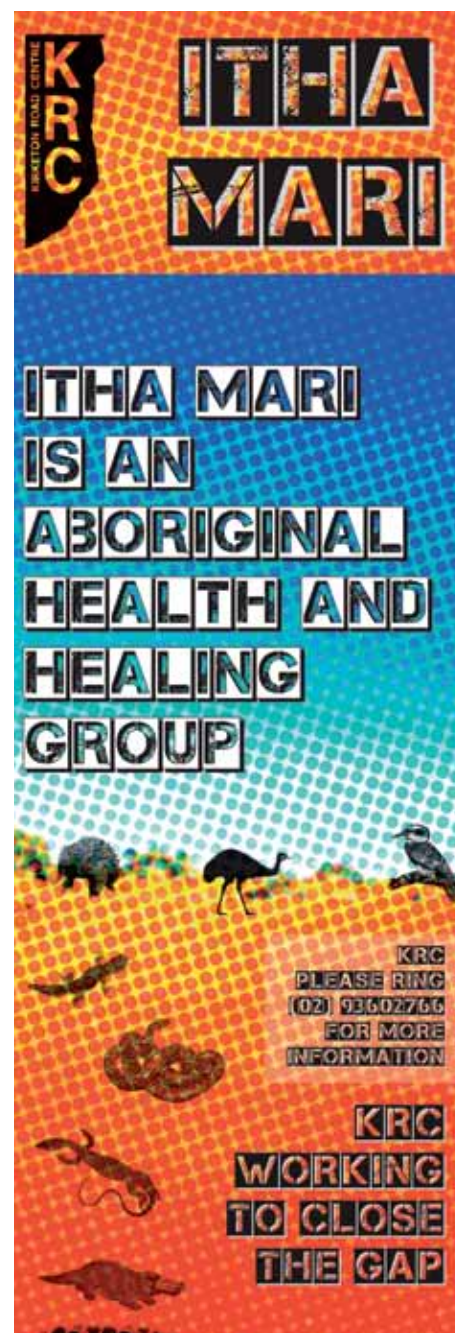
The project was developed after a KRC staff member was asked by a client of *Itha Mari* to help her learn to read and write 'well enough to fill in a form'. Education is one of the strongest indicators of health success. KRC, as a comprehensive primary health care service, and Tranby, as Australia's oldest independent Aboriginal adult education provider, jointly applied for a network model based on the shared goals of strengthening the skills and improving the capacity of Aboriginal clients.

Tranby's and KRC's aim was to improve the ongoing development of Aboriginal communities' capacities through: improving literacy skill levels of Aboriginal clients; strengthening partnerships with Aboriginal clients, as stakeholders with government and non-government agencies; increasing the level of awareness of Aboriginal issues as they impact on health and wellbeing; encouraging participation within a secure and safe framework to further enhance and build individual confidence and self-esteem; and increasing opportunities for consultation between clients and educational and health providers to develop programs that directly reflected their needs. The project was an outstanding success, not just for the gains in literacy but for the gains in clients' self-esteem and self-determination.<sup>5</sup>

### Storylines

At the start of 2015, a new initiative within *Itha Mari* was introduced. The Storylines initiative was based on the evidence-based practice of traditional yarning circles being utilised as a therapeutic tool for clients to engage with one another in order to reconnect with their countries, cultures and languages. These reconnections and strengthening of belongings in turn have had the capacity to improve health and wellbeing.<sup>6</sup>

The Aboriginal Elder David Wright, who worked as an Aboriginal Park Ranger with National Parks and Wildlife, attended this *Itha Mari* Storylines Group and led the yarning with tales of his work, his culture and his family, stressing the importance of good health and the links between health and Aboriginal self-esteem and Aboriginal community benefit. Uncle Dave also spoke of his broader life experiences and the importance of connection to country and culture. He shared and educated clients through his knowledge and skills with bush tucker and bush tools and



*Itha Mari* poster, incorporating spirit animals/totems with vibrant colours, reflecting powerful images of country.

implements.<sup>7</sup> All these shared activities were invaluable for clients who had been raised within urban environments and who felt that they had lost many connections to their lands, their cultures and communities.

Within *Itha Mari*, Storylines clients shared a range of narratives which differed in type and purpose, but which could clearly provide participants with a mechanism to manage current life transitions and recurring unresolved issues associated with loss, grief and trauma. In supporting clients to build connections to countries, cultures and communities, utilising the tradition of storytelling, *Itha Mari* allowed clients to share experiences of resilience, strength and courage.



*Itha Mari* has been supported and publicised through the publication of exquisitely beautiful fliers and posters developed in conjunction with the clients attending *Itha Mari*. At the clients' requests, these posters have incorporated their spirit animals/totems with vibrant colours reflecting powerful images of country.

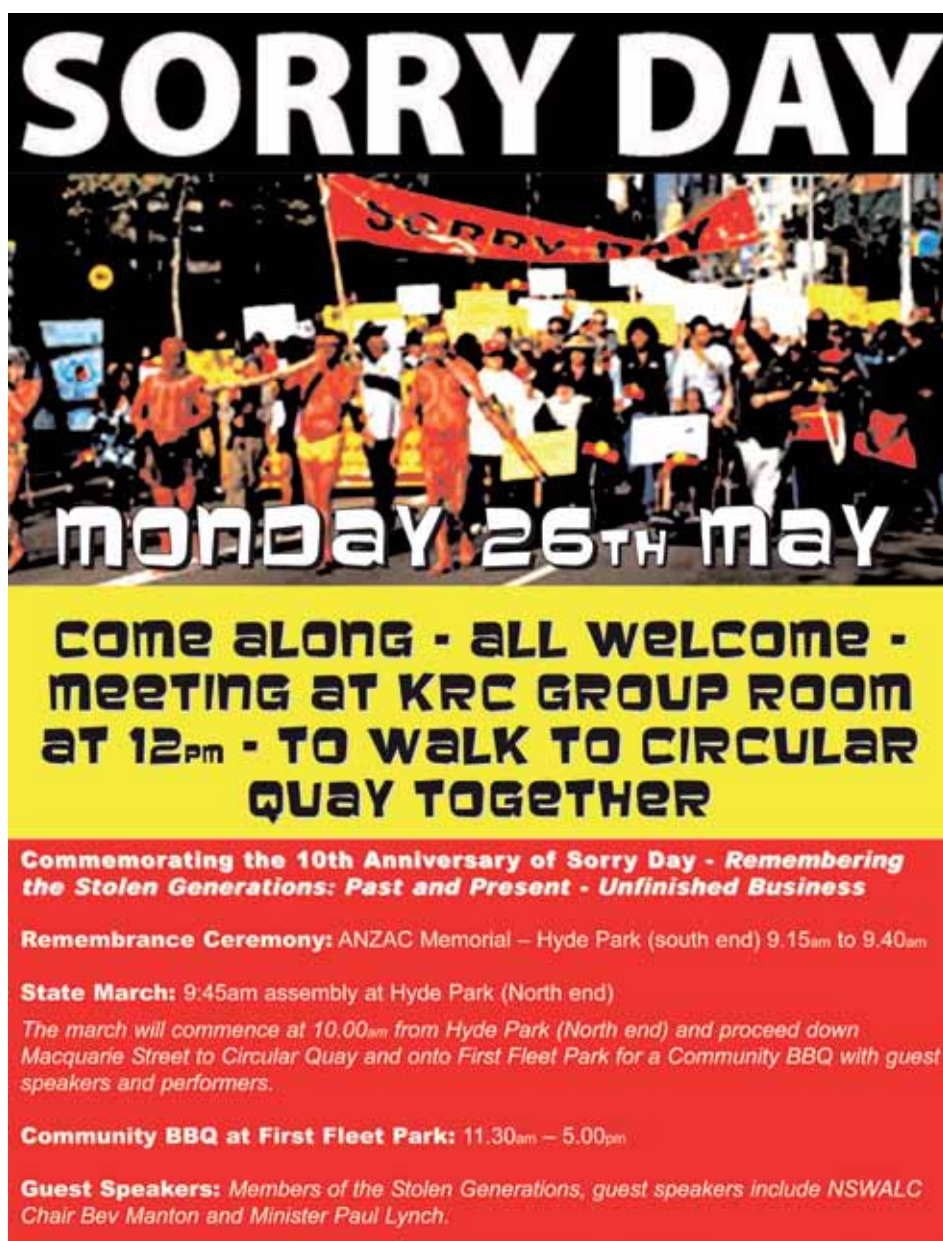
As well as empowering clients to access KRC, *Itha Mari* has been strongly linked to workforce development of KRC staff. *Itha Mari* has provided a platform for cultural competency and cultural respect training and has also kept Aboriginal clients' health issues at the forefront of KRC's service development and strategic planning as well as fulfilling the wider NSW Health strategies to improve health outcomes for Aboriginal peoples.

Significant challenges have presented as *Itha Mari* has evolved. However, with the determination of the participants and ongoing staff input and support, these challenges have been met with innovation and commitment, unfortunately though, not always with success. The clients attending *Itha Mari* reflect the high rates of mortality and morbidity within the broader Aboriginal community. These statistics continue as a shameful reminder of the continuing social, economic and political injustices with which Aboriginal peoples are faced daily. For KRC to continue to provide innovative and relevant programs for Aboriginal clients, there is ongoing commitment, assessment and evaluation of each of them, whether delivered within KRC as a health promotion activity or on outreach to The Wayside Chapel or the Medically Supervised Injecting Centre.

In conclusion, an affirmative program such as *Itha Mari* that is client-centred and promotes client self-determination, allows an environment of Aboriginal clients' confident participation in the service and the opportunity for positive health outcomes. For staff working under the banner 'health for all', *Itha Mari* remains an inspiration and provides for deeper understanding of KRC's Aboriginal clients and their stories of strength, courage, resilience and survival.

### Acknowledgements:

Brian Doyle and Miki Griffiths – Aboriginal project officers; Aboriginal and Torres Strait Islander clients of



KRC Sorry Day march flier, May 2008.

Kirketon Road; Gadigal people of the Eora nation, on whose land Kirketon Road Centre staff work; and all staff and clients of the Kirketon Road Centre.

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# The Connection: a strong and active voice for the health of Aboriginal and Torres Strait Islander young people who use illicit and injecting drugs

By Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)

The Connection – a program of the Canberra Alliance for Harm Minimisation and Advocacy (CAHMA) – is a peer-based service that represents the interests of Aboriginal and Torres Strait Islander people who use illicit and injecting drugs (PWID) in the ACT.

The Connection promotes improved health and reduction of harms associated with illicit/injecting drug use through a range of services, including peer support, representation and advocacy, referrals, information and education. This article takes a brief look at the history of this unique service, and outlines some of its main achievements.

## Breaking new ground

From 2003 to early 2004, AIVL (Australian Injecting and Illicit Drug Users League) ran a two-hour weekly workshop with local Aboriginal PWID in the ACT. The workshops were designed to educate and inform this community on topics such as hepatitis C, harm reduction and safer drug use. The Aboriginal PWID involved in the workshop (most under 25 years old) also worked with AIVL on developing a training program to be run with Aboriginal health workers.

In 2004, a group of these young people travelled overnight to Sydney to stage a cultural performance and run the training workshop at the Social Research Conference on HIV, Hepatitis C and Related Diseases (HHARD). The performance and workshop – and the discussion that followed – was truly ground-breaking. For many in the room, this was the first time that many of the issues affecting the lives of Aboriginal<sup>1</sup> PWID had been discussed so publicly. The discussion was lively and emotional, and highlighted just how much work was needed to ensure that the needs of Aboriginal people who use drugs were not only heard, but actually addressed by the health sector.

A number of the young people subsequently approached AIVL for support, with the aim of continuing this work by building a bigger and broader project. During this time, the Youth Coalition of the ACT (YCA) also became involved and the young people, together with AIVL, set up a partnership to develop a DVD to promote the work being done by young Indigenous people who use drugs.

The DVD, titled *Hang'in Not Hang'in Out*, was launched with a major party at the YCA office in August 2004. It featured all the participants from the original workshops discussing the issues they faced on a daily basis including drug use, housing issues, police harassment, family problems, racism and more. The launch was attended by local services, young people and politicians, and was a fantastic way to gain recognition for the amazing work being done by these young Aboriginal people, and to publicly ask for support from the ACT community to keep this work going.

AIVL assisted the young people to look for funding to help them to set up a drop-in space, so they could continue to meet and have a safe space where they could support each other. While looking for funding, the young people continued to meet each week through support from AIVL, and it was at this time that the relationship with CAHMA began.

The performance and workshop – and the discussion that followed – was truly ground-breaking. For many in the room, this was the first time that many of the issues affecting the lives of Aboriginal people who use illicit and injecting drugs had been discussed so publicly.

## The Connection is born

A proposal for a three-year project was submitted to the Foundation for Young Australians (FYA) in September 2004. This proposal outlined plans for a peer-based Indigenous youth drop-in centre and peer education and support service run by and for Aboriginal users and ex-users under 25. It also came up with a name for the proposed service: 'The Connection' – symbolising the connections young people had with each other and the connections they hoped to make with other young people and services and the community.

In late 2004, AIVL and the young people received the news that the proposal had been successful! Out of eight Stage 1 grants awarded nationally, only four would go on to receive a Stage 2 grant for the next three years. The Connection was born!

Around this time, Booker prize-winning novelist Arundhati Roy was visiting Australia to accept the Sydney Peace Prize. She had heard about the work of The Connection and decided to donate money from the prize towards the organisation.

## Taking root and growing

In 2006, John Van Den Dungen became The Connection coordinator. He remained in this role for five years. During this time, John was a runner-up for Young Australian of the Year Award.

From its humble beginnings, opening for a few hours a week in one very small room in the Griffin Centre in the heart of Canberra, the Connection went on to be auspiced by AIVL, becoming a strong and active voice for Indigenous youth in the ACT. Building on the base funding from the FYA, the Connection then received funding from ACT Healthpact for the Healthy, Mobile Mothers and Babies Project (funded by the Department of Family Services and the Office of Aboriginal and Torres Strait Islander Health [OATSIH]).

Because of these developments, in June 2006, the Connection employed five permanent paid peer workers (all under 25 years old, and two under 20), and engaged numerous volunteers and many participants. The service moved into bigger premises in the newly built Griffin Centre and expanded its opening hours to four days per week.

The Connection ran a peer drop-in centre which offered peer education, support, advocacy, referral and information. The drop-in centre provided a safe space for youth in Canberra where they could get a free meal and relax. The Connection also ran a number of other programs at this time and received enough funding to hold regular outings and social events for participants of these programs.

### Major achievements

The Connection continues to be funded by the Commonwealth and is now a program of CAHMA. The service receives around \$86,000 per year. This money covers, wages, rent, admin costs, phone, electricity

and computer bills, insurance, printing and training and education.

The service has had many major achievements to date, including:

- input in to the *Third National Aboriginal and Torres Strait Islander Blood Borne Virus and Sexually Transmissible Infections Strategy 2010–2013*
- along with CAHMA, the establishment of Australia's first take-home naloxone program
- input into the ACT Opioid Treatment guidelines
- participation in the ACT Alcohol, Tobacco and Other Drug Minimum Qualification Strategy (MQS)
- participation in the ACT Alcohol, Tobacco and Other Drug Minimum Qualification Strategy (MQS)
- receiving a YOGIE Award from the Youth Coalition of the ACT; an ACT Workers Group Award; and a National Crime and Prevention Award.

Of particular importance was the Connection's input into the *Third National Aboriginal and Torres Strait Islander Blood Borne Virus and Sexually Transmissible Infections Strategy 2010–2013*. In formulating this input, we held consultations with peers from our community to ensure that our voices were heard. This work has meant that Aboriginal and Torres Strait Islander people who use drugs are not only named as a priority population within the Strategy, but are highlighted as individuals who should be providing education and information on blood borne viruses.<sup>2</sup>

Another important achievement was the establishment of Australia's first peer-administered take-home naloxone program, which was started by CAHMA and the Connection in 2011. This program allows opioid users, their family and friends ready access to this lifesaving opioid overdose reversal drug. Experts in the alcohol and other drugs field, including researchers, doctors – and of, course peer organisations – have been lobbying for this approach to be introduced for over 20 years through publishing papers outlining international evidence and other lobbying efforts. The ACT program has been a huge success, and following its commencement, a few other states have since begun take-home naloxone programs.

The Connection was also an integral part of the lobbying efforts calling for a needle and syringe (NSP) in the ACT prison, the Alexander Maconochie Centre. The ACT government has given in principle support for this program but unions representing prison staff are highly resistant to the idea. Our advocacy in this area continues.

### References

- 1 For the purposes of this article, use of the term Aboriginal is inclusive of Torres Strait Islander peoples.
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The logo for HIV Australia, featuring the words "HIV" and "AUSTRALIA" in a bold, orange, sans-serif font. The letters are thick and blocky, with "HIV" stacked above "AUSTRALIA".

## Got something to say?

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HIV Australia publishes letters and contributions from readers. If you want to respond to something you have read here, or have an idea for an article, please write to us at: [editor@afao.org.au](mailto:editor@afao.org.au)



# Reconciliation and responding to HIV in remote Western Australia

By Lisa Tomney and Andrew Burry

When launching our Reconciliation Action Plan two years ago and setting out on our personal and organisational reconciliation journey, we didn't fundamentally change our commitment to serving Aboriginal and Torres Strait Islander communities. Such communities are identified as priority populations in all of our contracts and reflect in all of the State and National Strategies we are aligned with.

What reconciliation is doing for us, however, is changing our perspective on how and why we work with community. For decades we have been concerned about whether our services are culturally secure and appropriate. As contractually required by government, we report every six months on the numbers of Aboriginal and Torres Strait Islanders accessing our suite of services. Where we can, we report on service outcomes, suggesting ways they can be improved, and on emerging issues and challenges.

What could be clearly seen is that our services experience a wide disparity in Aboriginal use. Where 40% of clients using our fixed Fremantle Needle Syringe Exchange Program (NSEP) are of Aboriginal or Torres Strait Islander descent, at M Clinic (a service providing sexual health screening services for gay and other homosexually active men) just four out of 3,500 registered clients report Aboriginality (0.11%).

It would be easy to conclude, of course, that NSEP provides a culturally secure service whereas M Clinic does not. But reconciliation tells us that this is not a helpful or accurate conclusion to come to. Because, what the principles of reconciliation and substantive equality should be reminding us, is that Aboriginal and Torres Strait Islander gay men have exactly the same right to access a free, convenient and appropriate sexual health screening service as every other gay or homosexually active man. So the challenge is not to try and make M Clinic 'a bit more

Aboriginal', but to engage with Aboriginal and Torres Strait Islander communities and learn what a sexual health screening service that is comfortable and secure for the community to use would look like. Then, we can see whether M Clinic can fulfil that role, and if it can't then we must find a way to develop a service that does. This is what reconciliation is telling us, and it applies to everything we do.

## The tyranny of distance

Western Australia is Perth-centric and the WA AIDS Council is a Perth-centric organisation. Nonetheless, we recognise and welcome a social and community responsibility to provide equitable access to everything we offer for all Western Australians.

We have a long and proud history of working in support of Aboriginal and Torres Strait Islander people living with and/or affected by HIV, as well as in delivering culturally secure prevention support to metropolitan, rural and remote communities. Covering an area of 2.646 million km<sup>2</sup> presents obvious geographical and cost challenges. From Perth to Broome, for example, is a quick 24 hours by road (2,239 km) or two and a half hours by air. The so-called tyranny of distance makes the development of partnerships crucial and we have over the years built and fostered relationships with

Aboriginal Health Agencies, community organisations and Population Health units, and these have enabled successful working relationships that ensured delivery of support and education where most needed, some of the time.

A welcome outcome of this approach is that of the 68 Aboriginal and Torres Strait Islander people living with HIV in Western Australia, 40 have a varying degree of engagement with our organisation and services.

In terms of ongoing programmatic responses, we are investing heavily in time and energy in some specific areas of activity; one of which is 'SHAPE'.

## Supporting Health and Personal Empowerment (SHAPE)

In 2012, our outreach capacity and ability to intensively engage with our clients was boosted with the successful implementation of the SHAPE Outreach Program. The SHAPE team work within a model that embraces substantive equality and flexibility, allowing ongoing review and adjustment that supports better health, well-being and outcomes for our client group. Our team focuses on building relationships with our Aboriginal and Torres Strait Islander clients at their own pace, in an environment which is safe, supportive, culturally appropriate

... what the principles of reconciliation and substantive equality should be reminding us, is that Aboriginal and Torres Strait Islander gay men have exactly the same right to access a free, convenient and appropriate sexual health screening service as every other gay or homosexually active man.

and with an approach that develops trust and self-directed engagement. Feedback from clinicians indicates that SHAPE has assisted significantly in supporting clients to remain linked with health services, achieve adherence with HIV medication, and receive additional referral to appropriate health and wellbeing services. The SHAPE team works beside clients to ensure all presenting issues can be considered as part of a comprehensive support plan, including secure and affordable housing, financial security, inter-agency advocacy, family support and addressing social isolation.

Although SHAPE is Perth-based, it works together with our other support worker teams with clients from the far corners of our jurisdiction, who are frequently obliged to come to Perth as the only possible site of effective specialist medical attention.

### World AIDS Awareness Week in the Kimberley

During December 2014, our Positive Peer Educator (Liz Walker), was invited by Kimberley Aboriginal Medical Services Ltd (KAMS) to provide HIV education and a personal perspective to communities in Broome, Kununurra and Wyndham. Liz was accompanied by our Aboriginal and Torres Strait Islander Health Promotion Officer (Dennis Beros). Presentations were provided to Broome Senior High School, Kununurra District High School, Save the Children girls group, Broome, Kununurra and Wyndham Hospitals, KAMS, Yawuru Community Group and Wyndham work camp. During the five-day tour over 200 youth, 80 medical and allied health professionals, and 35 community members were engaged, and we conducted five radio interviews, one online article, tweets and Facebook updates.

All presentations were met with great enthusiasm, suggesting that there is genuine thirst for face-to face support to supplement that provided electronically and by telephone. Conversations amongst participants identified barriers for clinicians in offering testing, pre- and post-test discussions, issues around contact tracing in the region, and practical measures that will support people living with HIV in rural and remote communities. It was also possible to begin to understand the communities' readiness to address issues around sexual health.



**Pictured top and above:** Liz Walker and Dennis Beros engaging with community health workers and community leaders in the Kimberley region, Western Australia, November 2014.

### Sustainability

Whilst our initiatives have demonstrated at times outstanding outcomes – and certainly great promise – there remains a concern about their level of sustainability given their dependence on patchy and insecure funding. As an organisation built by and living on the principles of the Ottawa Charter for Health Promotion, we recognise that lasting change comes only when capacity within communities is developed and individuals within those communities have a sufficient level of empowerment to enable them to respond directly and safely to their own health needs; better still, to be enabled to insist on the kinds of services that are most relevant and helpful.

Far too absent in the planning and implementation of programs across our state are the voices, thoughts, ideas and insights of Aboriginal and Torres Strait Islander people. Until we find a way to listen more closely, learn more carefully, and work more sensitively, we will not deliver equitable access to services most needed.

Our reconciliation journey keeps telling us this.

**Lisa Tomney is the Manager, Clinical Services at the WA AIDS Council. Andrew Burry is the Chief Executive Officer of the WA AIDS Council.**





*Community Hands, Tristan Templar, Tas.*

## Increasing visibility and participation of Indigenous peoples at AIDS 2014 and creating a cultural legacy beyond the conference

By **Michael Costello-Czok**

In July 2014, the 20th International AIDS Conference (AIDS 2014) and the International Indigenous Pre-conference on HIV & AIDS were held in Australia for the very first time. Planning and development of AIDS 2014 and affiliated events sought to ensure greater visibility and participation of Indigenous peoples.

Leading up to AIDS 2014, Australian Aboriginal and Torres Strait Islander representatives working in HIV partnered with the International Indigenous Working Group on HIV and AIDS (IIWGHA) to establish the Australian Aboriginal and Torres Strait Islander Organising Committee (AATSIOC).<sup>1</sup>

Funded by the Commonwealth Department of Health, the Committee enabled effective coordination of a range of activities throughout AIDS 2014. But beyond AIDS 2014, the relationships formed are a conference legacy that will support and sustain our work into the future.

### **Our Story, Our Time, Our Future**

The International Indigenous Pre-conference on HIV & AIDS was held in Sydney from 17 to 19 July 2014, just prior to AIDS 2014. The Pre-conference theme of Our Story, Our Time, Our Future, was developed to capture the

spirit of Indigenous world views, our cyclical approach to eternal life, our ways of learning and sharing knowledge and the importance of future generations and custodianship of our traditional lands. The Pre-conference attracted close to 300 delegates, including large numbers of people living with HIV, elders and youth. More than 100 of the delegates went on to attend AIDS 2014 in Melbourne.

Other significant AIDS 2014 initiatives included coordination of the Indigenous Peoples Networking Zone at the conference venue in Melbourne, development and launch of the Eora Action Plan on HIV 2014, establishment



*Looking East, Raymond Zada, SA.*

of the Aboriginal Nations and Torres Strait HIV Youth Mob (ANTHYM), and launch of the Aboriginal and Torres Strait Islander HIV Awareness Week, to coincide with World AIDS Day each year from 2014 to 2017.

### One Handprint tells many stories

As part of these activities, a major exhibition of Aboriginal and Torres Strait Islander art was launched at the Indigenous Pre-conference. The *HANDPRINTS* exhibition brought together the work of nine Aboriginal and Torres Strait Islander artists from each Australian state and territory, including the Torres Strait Islands. Each

artist was commissioned to create an artwork that incorporated personal and community stories relating to the impact of HIV.

*HANDPRINTS* was designed to promote a broader understanding and appreciation of Aboriginal and Torres Strait Islander culture as part of the HIV response. Our ancestors' use of handprints and ochre has long recorded our history, our presence and our life journeys. Our art and storytelling are intrinsically linked to our cultures. Our art describes our Dreaming – our creation, our land, our people, our wildlife, our totems and our journey together.

Our ancestors' use of handprints and ochre has long recorded our history, our presence and our life journeys. Our art and storytelling are intrinsically linked to our cultures.

The project incorporated a groundbreaking approach to HIV education and prevention through an art exhibition, sharing diverse stories about the impact of HIV and Aboriginal and Torres Strait Islander communities. Artists were excited and enthusiastic to be involved with this project, with many of the artists expressing interest in creating more art for HIV education and prevention work.

Following its fantastic reception at the Sydney International Indigenous Pre-conference and at AIDS 2014 in Melbourne, *HANDPRINTS* is now being incorporated into the Aboriginal and Torres Strait Islander HIV Awareness Week, with the artworks being utilised as HIV health promotion and educational resources and exhibited nationally.

The following artists were engaged in the *HANDPRINTS* project:

- Arone Meeks, QLD: *I am not the problem' our journey through HIV*
- De Greer-Yindimincarlie, NSW: *Shayme*



- Jukuja Dolly Snell, WA: *Kurtal*
- Nicky Newley-Guivarra (Nigooli), Torres Strait: *It's Ok*
- Patrick Ahkit, NT: *HIV and the Power of 'Connection' We are Never Alone*
- Peter Waples-Crowe, VIC: *Koori Threats and Resistance*
- Raymond Zada, SA: *Looking East*
- Tristan Templar, TAS: *Community Hands*
- Uncle Jim Boza Williams, ACT: *Bogan Moth*.

This year, *HANDPRINTS* will be exhibited in the Foyer of the South Australian Health and Medical Research Institute (SAHMRI), allowing the artwork to be exhibited for the first time in Adelaide. **Location:** foyer of the South Australian Health and Medical Research Institute North Terrace. **When:** Monday 23 November to Friday 4 December, 2015. Open daily from 9am–5pm. Admission is free. The *HANDPRINTS* project is generously funded by the Australian Government – Department of Health.

**Michael Costello-Czok is Executive Officer of the ANA and a guest editor of *HIV Australia*.**

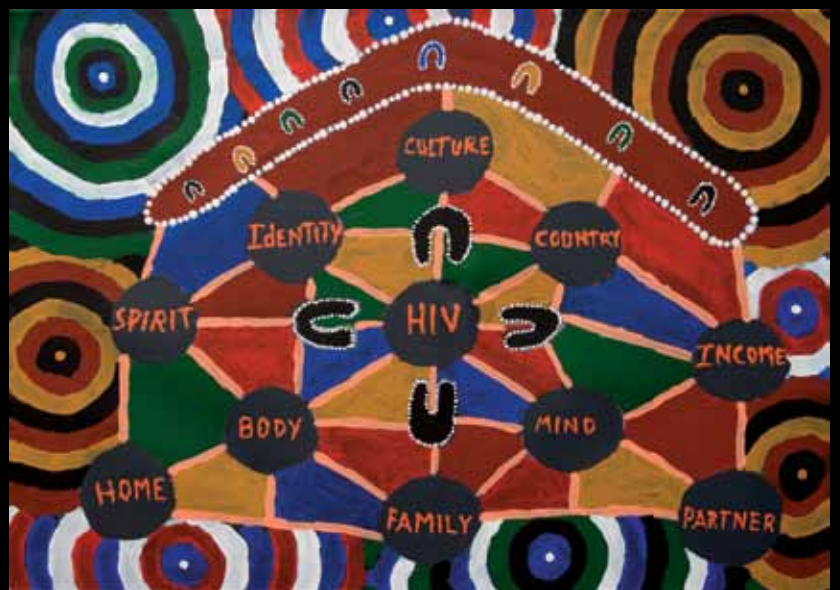
### Endnote

- 1 James Ward, Convenor – South Australian Health and Medical Research Institute; Michael Costello-Czok, Co-convenor - Anwernekenhe National HIV Alliance (ANA); Neville Fazulla – Positive Aboriginal Torres Strait Islander Network (PATSI); Michelle Tobin – ANA; Mark Saunders – National Aboriginal Community Controlled Health Organisation (NACCHO); Brett Mooney – Torres Strait and AIDS Council Representative; James Saunders – Aboriginal Nations and Torres Strait Islander HIV Youth Mob (ANTHYM); Sallie Cairnduff and Darren Braun – Aboriginal Health and Medical Research Council of New South Wales (AH&MRC); Kat Byron and Peter Waples-Crowe – Victorian Aboriginal Community Controlled Health Organisation (VACCHO); Meggan Gross and Victor Tawil – NSW Health; Trevor Stratton IIWGHA Co-ordinator; Canadian Aboriginal AIDS Network (CAAN).



*Kurtal*, Jukuja Dolly Snell, WA.





**Pictured top:** *Shayme*, De Greer-Yindimincarlie, NSW;  
**centre:** *Bogan Moth*, Uncle Jim Boza Williams, ACT;  
**and right:** *HIV and the Power of "Connection" We are Never Alone*, Patrick Ahkit, NT.





**Pictured clockwise from top left:** *Koori Threats and Resistance*, Peter Waples-Crowe, VIC; *'I am not the problem' our journey through HIV*, Arone Meeks, QLD; and *It's Ok*, Nicky Newley-Guivarra (Nigooli), Torres Strait.



BE PART OF THE

**HIV FREE**  
GENERATION!

Mural from Narooma High School

## HIV Free Generation: AH&MRC Street Art Project

By Sallie Cairnduff, Darren Braun and Kaylie Harrison

'It was real good spray painting and stuff, we had a lot of fun. And we learnt more about HIV which I didn't even know what it meant when I first went to class'. — Participant

### Introduction

Over the last few years, the Aboriginal Health and Medical Research Council of NSW (AH&MRC), in partnership with Aboriginal Community Controlled Health Services (ACCHSs), Local Health Districts (LHDs) and other non-government organisations (NGOs), has used an arts-based approach to successfully engage young Aboriginal people in health promotion activities around sexual health and drug and alcohol use.

Recent state-wide projects, including 'It's Your Choice, Have a Voice', 'Where's the Shame? Love Your Liver' and 'Staying Strong: Act Connect Survive', have provided Aboriginal young people with relevant health education as well as engaging them in writing and filming songs and creating hip-hop dance routines. Evaluations of these and other projects have demonstrated that an interactive arts-based approach is an effective way of engaging young Aboriginal people on topics that might otherwise cause shame.

### About the project

Inspired by the 2014 International Indigenous Pre-conference on HIV and AIDS, AH&MRC identified a need to refocus activities with young Aboriginal people around HIV, STIs and injecting drug use.

The HIV Free Generation Street Art Project is based on the hepatitis C project, 'Your Mob My Mob Our Mob', which was run by the AH&MRC, in partnership with Hepatitis NSW in 2012–2013 and delivered in five juvenile detention centres and in three community settings. The 'HIV Free Gen' project aims to increase knowledge of prevention, testing and management of HIV, sexually transmissible infections (STIs) and hepatitis C among Aboriginal young people (15–25 years old).

In partnership with ACCHSs, the project was delivered in four locations from December 2014–June 2015, involving schools, youth services and other local services.

The project consisted of the following:

- **Interactive educational activities**, that included peer to peer learning as well as focusing on positive sexual health messages
- **Street art** as a way to engage young Aboriginal people, and to leave a mural as a permanent contribution to the community
- A **social media** component to encourage further reach to peers
- **Community engagement** through a launch of the final mural and BBQ
- **Capacity building** component through working with participating ACCHSs.

Thirty-eight young Aboriginal people (8–11 per site) participated in the face-to-face education activities and mural development, and a further 2,000 people were reached via the social media component of the project.

### Project format

The AH&MRC developed a program template, which was adapted to local needs and the skill and confidence of local workers. In the majority of locations, the project was organised and delivered by experienced Aboriginal STI HIV and hepatitis C workers. In other locations, local workers were less confident in delivering education to young people, and additional support was provided. AH&MRC also provided STI, HIV and hepatitis C resources and information.

Education tools were taken from AH&MRC's resource, 'DOIN 'IT' RIGHT!' These included interactive activities focusing areas such as risk, self-esteem and STIs, and games such as condom races.

The project ran over three days in each location, and was tailored to the groups' ages and interests. During the first two days, the young people participated in structured activities focusing on STIs, HIV and hepatitis C, and then worked with a professional street artist to create a mural that communicated key messages they had learnt. The third day focused on launching the mural to the wider community, as well as celebrating what the young people had learnt and designed.





Mural from Kempsey

To extend the reach of the messaging, photographs taken throughout the mural development process were posted on the ‘HIV Free Generation’ Facebook page. In three locations, a short film clip that included vox pops with participants and workers, was developed and posted on Facebook.

### Engaging young Aboriginal people through street art

Ash Johnson, a professional street artist, provided participants with an overview of street art etiquette, the history of street art, health and safety, and assisted the young people to design and create a mural communicating key messages which emerged out of the education component.

The murals were created in prominent places – a school wall at Blacktown Youth College, a number of walls at Narooma High School, on an external wall at the entrance of the Durri Aboriginal Corporation Medical Services (at Kempsey) and internally at Tharawal Aboriginal Corporation (at Airds). As they are permanently on display, the murals continue to generate discussion in the

community, and participants involved in the project have ongoing opportunities to share knowledge with their peers. At one service, the murals resulted in discussions with board members about the role of sharing injecting drug equipment in transmitting HIV, which has led to further work around improving harm minimisation activities for the area.

The language and messages used by the murals reflect the strengths-based STI and HIV education that young people had been participating in, for example:

- “Check yo’ self B 4 U wreck yo’ health” – to encourage STI testing (Blacktown Youth College)
- “Knowledge is power, let’s make it go VIRAL” (Narooma High School)
- “Don’t stress, Get a test” (Kempsey)
- “Don’t be shame, be game” to encourage condom use (Kempsey)
- “You and Me – then let’s talk about HIV” – to discuss sexual transmission of HIV (Airds).

The imagery depicts strong and proud young Aboriginal people making informed choices about their sexual health.

Feedback from the young people is overwhelmingly positive about the street art component, and was identified by some of the workers as one of the key reasons young people continued to participate in the three-day project.

*‘I think they loved it and they’ve loved that two walls have been done in areas that Aboriginal kids hang around.’*

— Worker

### Capacity building and partnerships

AH&MRC supported services to deliver this project by providing a framework for project delivery, including an education session plan. These plans were adapted according to needs identified by the community (e.g., to focus on injecting drug use, or sexual health education), the age range of the participants and the confidence and skills of the local workers.

Services were required to participate in a pre-project workshop to prepare for the project, and were provided with templates for inviting schools to participate, consent forms for participants and resources



Mural from Tharawal Aboriginal Corporation

to deliver the education component. ACCHSs identified partner organisations and groups of young people to invite, prepared a wall or space for the street art component, and organised the community launch.

### Social media

As the number of participants in each location was small, the reach of the project was extended through social media, managed by AH&MRC's Sexual Health Project Officer. As of October 2015, the page had nearly 300 'likes' and one post had a reach of more than 1,900 people and more than 700 views.

Naya Ngarra Productions, an Aboriginal media company, were contracted to develop a short video at three locations (Blacktown School, Narooma and Kempsey). The purpose of the videos was to extend the reach of the project outside of the local area, as well as to capture some of the thoughts of the participants for evaluation purposes. The videos have proved to be very popular in increasing reach of the social media site.

### Community engagement

Local community members were invited to participate in the project through the launch of the mural. Hospitality students from Blacktown Youth College got involved by providing catering for the launch, while at another service, the mural was launched at the organisation's Christmas lunch. At most locations, parents, workers, board members, school principals and other staff attended the launch.

### Impact

*I want to be one of the HIV generations. I want to make sure that people stop the risk of HIV.*

— Participant

The impact of the project has been collated through pre- and post-workshop evaluations, vox pops comments, and debriefs with workers.

At all locations, participants were encouraged to do pre- and post-project evaluations, via a short true/false quiz. In some locations it was found that literacy was an issue, so data was also collected via the comments young people made on social media.

From the pre- and post-evaluations, it became clear that there was existing knowledge about HIV transmission through sex without using a condom and blood-to-blood contact. There was some confusion around HIV transmission through sharing cutlery, which improved after the workshop was delivered, and there was also increased knowledge about services available for young people.

Workers indicated that some of the benefits of the project included: continued discussions around HIV/STIs in local communities; an increased interest in services and young people being engaged in sexual health promotion activities; having highly visible artwork on display that young people can be proud of, relate to and identify with; and evident enthusiasm and pride in being involved with the project.

*'Young people who don't normally come to school, to come into college and then give up their holidays to work on this project for 3 whole days, it's outstanding.'*

— Worker

**To view the HIV Free Generation photos and videos, please visit: [www.facebook.com/YourMobMyMobOurMob?ref=hl](http://www.facebook.com/YourMobMyMobOurMob?ref=hl)**





Mural from Aboriginal Medical Service Western Sydney – Blacktown Youth College.

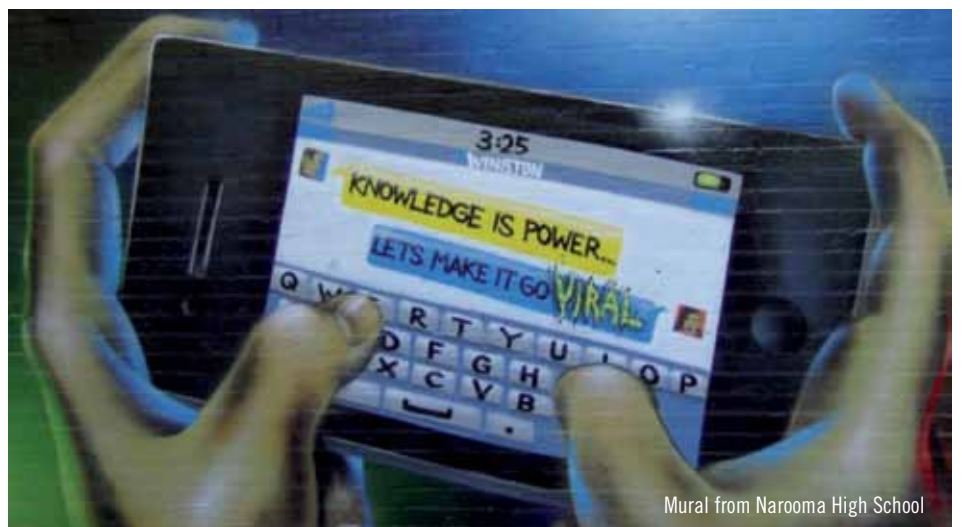
### Acknowledgements

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Mural from Kempsey

Sallie Cairnduff is Manager of the Public Health Unit at the The Aboriginal Health & Medical Research Council of NSW (AH&MRC), Darren Braun the previous Sexual Health Project Officer, and Kaylie Harrison the Senior Public Health Project Officer. The AH&MRC is the peak representative body and voice of Aboriginal communities on health in NSW. The AH&MRC represents its members, Aboriginal Community Controlled Health Services (ACCHSs), which deliver culturally appropriate comprehensive primary health care to their communities.



Mural from Narooma High School

# INTERNATIONAL FEATURE

## Indian Blood: HIV and Colonial Trauma in San Francisco's Two-Spirit Community

By Andrew Jolivette

Indian Blood<sup>1</sup> is a study conducted by Professor Andrew Jolivette, exploring the intersection of gender, sexuality, mixed-race identity and HIV among mixed-race, lesbian, gay, bisexual, transgender, queer, and/or two-spirit (MLGBTQ2s) identifying American Indians living in urban areas.

The following is an abridged version of a speech Andrew delivered at the 2015 Australasian HIV & AIDS Conference in Brisbane on 18 September.

*Halito. Buenas tardes. Bon Jour. Kia Ora.* Good afternoon. Much respect to the Jagara people and the Turrbal people, for allowing me to speak on your country. I also want to acknowledge the other Aboriginal and Torres Strait Islander peoples of this country. I come here humbly and as a guest with an open heart and a thankful spirit for all that you and your ancestors share and sacrifice so that we might all gather here today as Indigenous peoples of the earth.

I am the son of Annetta and Kenneth, the grandson of Gertie and Howard and Isabella and Andrew. The great-grandson of Allie and Eli, Francois and Rosina, Eva and Edward, and Curtis and Leila. I come from the Opelousa and Atakapa nations of southwest, Louisiana. Of a mixed-blood Afro-Latin people – made-up of the lifeblood of American Indians, West Africans, and Latin Europeans. I introduce myself in this way so that you will know who I am and where I come from as a fellow Native, Indigenous person and as a fellow relation.

Today is our day. Today is our time. Today is our day to tell our stories and to remember and reflect on all we have struggled through and all that you have accomplished since the onset of the HIV/AIDS epidemic over 30 years ago.

Today I share the story of fifty Indigenous American Indian mixed-blood men and transgender identified people from the San Francisco bay Area who represent over two-dozen different nations. In sharing their story today, I also share my own story.

I'd like to open this story with a quote and a short passage from the introduction to my new book, *Indian Blood: HIV and Colonial Trauma in San Francisco's Two-Spirit Community*.

*HIV and AIDS is something that I have learned to live with. It's also something that a part of me feels happened for a reason. I wasn't sure if I should disclose my status in this way here today. I spoke*

*with a colleague about it and he said, "How will disclosing impact you? Will it benefit you? Are you giving anything up?" I thought to myself, as a gay man of color, I have a responsibility to disclose. This is a very personal decision, but in indigenous communities and in communities of color we lack faces to make this pandemic real. If you've never known someone living with AIDS, now you do. You know my story and in sharing it I hope that others will know that they can live with this. They can have a career, a family. They too can find love again. Over the past three [eleven] years I have learned AIDS is not me. I am me. AIDS is only one other part of my life.*

The quotation that opens this chapter comes from a mixed-race, gay, American Indian man. His story is not an uncommon one. For American Indian people today, HIV/AIDS, gender, sexuality, and mixed-race identity intersect in complex and traumatic ways in the absence of community support, cultural buffers, and stress-coping mechanisms to combat colonial oppression.

This is my story too. I open with my own story because I deeply believe in the practice of research justice. Research justice is about seeking solidarity with research participants. It is about working with, not on research participants to weave a narrative, a set of life histories captured in one of many moments in time. In fact, to understand the very nature of the colonial haunting that has displaced, removed, relocated, and perpetrated mass acts of genocide (i.e., kidnapping, boarding school abuse, sexual assaults, murder, forced sterilisation etc.) against Indigenous peoples, researchers must understand the significance of what Maori scholar Linda Tuhiwai Smith (1999) has termed 'Indigenous methodologies.' Smith argues that for most Indigenous peoples because of the abuse and lack of access to write about our own communities, research is



considered a 'dirty word' to most Native peoples in the Americas and the Pacific.<sup>2</sup> Thus to build a research relationship based on solidarity and justice one must consider research as a ceremony.<sup>3</sup>

When I was diagnosed with AIDS nearly 13 years ago, in October of 2002, I had 35 T-cells and a viral load of over 500,000. I thought I was dying. I went through the scare of thinking I had liver failure which was the result of taking the drug Septra to fend off the pneumonia that had invaded my body. It turned out I was allergic to the medication which raised the enzyme levels in my liver. At the time of my diagnosis I was just 27 years old, a graduate student trying to complete a dissertation, at the same time that I was working a full-time job as a middle school dean and teaching as a part-time lecturer at San Francisco State University.

While I struggled and thought my life might be over, I never struggled in the way that the men and transgender people from my project with the Native American AIDS Project struggled. The way they and many in our communities struggle. I completed my dissertation and Ph.D. just five months after being released from the hospital, 25 pounds lighter at that time from the pneumonia ... I have still faced many health obstacles and personal struggles. In 2012, my mother passed away from breast cancer, and just a year and a half ago I myself was diagnosed with stage I prostate cancer. While my health has been a constant up and down battle, I see the bright light in sharing my story. When we open our hearts, when we become vulnerable, when we share our stories and our ancestors stories we start to heal, we become whole again. We find balance.

Because of my academic training and personal interest in mixed-race studies I set out to understand how experiencing life as Indigenous and mixed impacted one's chances for contracting HIV/AIDS. What I learned on the journey is that like so many other facets of Indigenous life today, colonialism still attempts to rob us of the ability to tell our stories and to be our full selves. The Indigenous people in the study shared so many painful and traumatic stories that were interconnected. These stories speak powerfully to the social and psychological patterns of what I term 'two-spirit cultural dissolution'. That is when we think about some of the



Andrew Jolivette delivers his address at the 2015 Australasian HIV & AIDS Conference, Brisbane, September 2015. Photo: Amanda James (James Photography Services), courtesy of Australasian HIV&AIDS Conference and ASHM.

traditional ways that same-gender loving Indigenous people around the world engage relationships and life we see that colonisation attempted to destroy that way of life and as that system of cultural support and well-being was dissolved so too were many of the necessary and foundational protective factors that can reduce risk for HIV transmission.

In *Indian Blood* – my study of the intersections of gender, sexuality, mixed-race identity and HIV – I examine the impact of colonial and neocolonial repression of Native agency and subjectivity through the development of

a Psychosocial Nexus of HIV Risk. The *Indian Blood* Psychosocial Nexus of HIV Risk Model (IBPN HIV Risk Model) outlines historical and contemporary factors impacting the spread of HIV/AIDS among MLGBTQ2s, and includes six interconnected psychological and social factors that produce high-risk sexual behavior. These factors include: two-spirit cultural dissolution, historical/ inter-generational trauma, gender and racial discrimination, mixed-race cognitive dissonance, sexual violence, and stress coping in urban Indian kinship networks.

I argue that as the spiritual, socio-economic, and cultural significance of two-spirit individuals dissolves – through colonial contact with Europeans – mixed-blood American Indian queer people experience ruptures in their social and cultural support networks that under normal circumstances would serve as protective factors against external discrimination. As discrimination against two-spirits increases from contact to the present there is a breakdown in traditional/tribally specific values, beliefs, and practices that lead to detrimental experiences with inter-generational trauma. These traumas within the context of the Mixed-Race LGBTQ and Two-Spirit experience are manifested through racial and gender discrimination, mixed-race cognitive dissonance, and sexual violence. If these traumas are left unaddressed from a diverse range of two-spirit cultural ethics then we can expect weak stress coping mechanisms within urban Indian kinship networks. The only way to create more effective harm reduction models is through a return to a two-spirit cultural ethic of support, inter-generational mentoring, and ceremonial healing.

I want to briefly share a few quotes from the participants in the study to more carefully explain the six interrelated factors that produce high risk for HIV among mixed-blood Native people. I want to say that while this study is small, and was done in one area of the United States, I do believe that it may speak to similar trends throughout the Americas and the Pacific.

### Factor 1: Two-Spirit cultural dissolution

*You know, I've been to places where I've met people, like myself on the reservation [who also attended boarding schools] but obviously didn't like themselves enough*

*because they didn't want to do nothing for themselves. But, um ... I got beat up. I got the shit beat out of me so bad you wouldn't even recognise me it was so bad. I got kicked in the face about 25 times by this guy with boots on. Just totally beat up on the reservation, nobody came to help, nobody helped me .... After leaving I got into a relationship but then I started using again. So it was like, you know what? You're gonna go back to the reservation and end up back where you were, go back down hill – sobriety. That's why I came here. I needed to get the sobriety. And that was the main thing. Because what was up there for me was no longer [working]. You know there was like ... a mile of death up there, really serious death up there. So to me, like when death is always open, all those old people are definitely gone, those people are definitely gone.*

— Indian Blood Focus Group Respondent, 2012.

The process of two-spirit cultural dissolution for MLGBTQ2s American Indians has taken place over many centuries and the damage brought forth by colonisation and on-going settler colonialism has led to the dissolving of two-spirit cultural support networks.<sup>4,5,6,7</sup>

The dissolution of two-spirit cultural practices is a direct result of religious missionaries and government officials who worked to erode, destroy, and reshape gender and sexual practices within Native communities throughout the Americas.<sup>8</sup>

### Factor 2: Historical and intergenerational trauma

*I grew up by myself and um, a lot of ducking and dodging, you know, a lot of it was just a constant. A constant life you know, so um, and my family didn't know how to deal with it cause my mother*

*was working all of the time, she didn't know what was going on, and I don't know, I was drunk a lot too, you know. I started smoking cigarettes, I learned how to inhale when I was about 5 or 6 years old and I liked it. I was smoking and my sister would let me smoke. By the time I turned 13, my mother allowed me to smoke cigarettes, she allowed me to smoke weed, she allowed me to do speed, she let me do whatever I wanted. As long as I did what I was supposed to do you know.*

— Indian Blood Respondent, 2012.

Historical traumas are culturally, economically, and spiritually transferring from one generation to the next leading to inter-generational traumas that are not only endemic within Native communities, but these experiences with trauma are also central to US policies of control, paternalism, and global imperialism.

### Factor 3: Gender and racial discrimination

*I'm short, I'm fat, and I'm red. And I ain't upset about it. When it comes to dominant culture I've never related. I mean never. I always look at values, well on the contrary I kind of take an opposing view, is that what they call it? Identity to me is still kind of problematic because of quote 'gay/queer' culture. I was never 'out', but I was labeled as being out, so I was the person that other people came out to, both male and female. Historically, I've always, ALWAYS, been at more comfort with um... female identity. Whether it's biological, mostly biological female, but it's just that femaleness. If I've got a choice, if I'm gonna kick it with the boys, hetero or gay or queer, or I'm gonna kick it with the dykes, I'm going with the dykes. Cause I can relate, I understand those dynamics.*

— Indian Blood Respondent, 2012.

Gender and racial discrimination is mitigated through stress-coping mechanisms that range from substance abuse to exercise, to cultural activities for the majority of participants in the study. Not every form of stress-coping equally reduces high-risk sexual behavior. In fact, some stress-coping strategies actually can increase risk for HIV/AIDS transmission among members of this population demographic.

As discrimination against two-spirits increases from contact to the present there is a breakdown in traditional/tribally specific values, beliefs, and practices that lead to detrimental experiences with inter-generational trauma.



#### Factor 4: Mixed-race cognitive dissonance

*Like ya know racially, I'm like a quarter white, but I don't feel white and I don't look white, so ... Um ... People can't often tell, cause I'm so mixed about what I am actually. So um... Like Latinos will think I'm Latino, Filipinos will think I'm Filipino. Ya know, some Asians will think that I might be part Asian or something, and Indian people will often think I'm Indian or Mexican or something. I'm just racially unidentifiable often. Um, I think that growing up I felt a difference between the way like white people feel about themselves and their privileges. Like I think they feel more entitled often to things. And I've actually seen that a bit in my family, because I know like the side of my family that's like Latino and Asian they came from a colonial place.. And also like my dad on the Cherokee side, he was racist too. He like did not like Black people. And I'm not sure if that was a part of being white or part of like the Indian side. And I sense, ya know, knowing what the community is like now in Oklahoma it's probably both. Yeah so I not only experienced racism, feeling discriminated against, but I also saw just people in my own family discriminating against other people. So I knew often the weird dynamics that race can play just in your own immediate family.*

— Indian Blood Respondent, 2012.

MLGBTQ2s feel both conscious and unconscious pressure to surrender their power in naming themselves in an ethnic/racial sense because other people will always expect the mixed-race subject to respond to the same fixed identity that they ascribe upon them. The ascription of ethnic and racial identity upon MLGBTQ2s also produces challenges in developing a congruent, collective social memory and sense of true community membership.

#### Factor 5: Sexual violence

*At the age of 8, I started, or I was being raped. I was raped from the age of 8 until I was 18. Right or wrong I actually did the one thing that they tell you not to do and I actually resisted, so I experienced some extreme violence.*

*I suppose I'm kind of a case study. I was just 8 when this all started. So the behavior that I took on displayed during that time, was atypical. I tried to resist. But yet it's in the American paradigm, let's blame the victim, and I was just a bad student. And it's like no I was just doing the best I could with, ya know, I was just doing the best that I knew how given the circumstances. Later I got into the BDSM [bondage, domination, sadomasochism] world. Hmmm, I wonder why? BDSM. Pain baby, pain!*  
— Indian Blood Respondent, 2012.

Two-Spirit Bodies (TSBs) experience psychological assault, physical violence, negation and erasure as a result of colonial and settler-colonial narratives concerning the performance of gender and sexuality within the singular context of Western categorical definitions that lead to what Eduardo and Bonnie Duran (1995) describe as soul loss.

#### Factor 6: Stress coping in an urban Indian kinship network

*It felt like ... It almost felt like just because we're Indian and we don't hang out or things like that but I mean ... I always wanted to be friends with Indians, but they always seemed kinda like I was ... I felt like not really Indian because I was raised by White people so it was kind of ... I was always kind of shy and I didn't identify with Indian issues. But um ... It was when I came to NAAP that I was able to find out about BAAITS and all these wonderful organizations that have to do with American Indian people. So I learned how to bead, and like all these wonderful things like I'd been wanting to experience all these wonderful things for many years and I never knew that I could because I just never thought about it.*

— Indian Blood Respondent, 2012.

Effective, ethnic-specific, and culturally competent health care practices can strengthen stress-coping mechanisms within urban Indian MLGBTQ2s communities while also reducing high-risk sexual behaviors that lead to the transmission of HIV/AIDS.

Well organised, consistent, and empowering urban Indian kinship networks can also reduce the psycho-social risk factors associated with the IBPN Model.

The culmination on this study will be a two-year cultural leadership, peer mentoring intervention. A Stress and Wellness Rubric will be developed to assess differences from the beginning of the intervention to the end to assess the effectiveness of the Inter-Generational Healing and Leadership Model on participants. Data and rubric measures will be published in peer-reviewed journals, and additional funding will be utilised to focus on a national study/intervention.

Let today be the beginning of a new day where blood is what sews us back together not what tears us apart.

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**Andrew Jolivet is Professor and Chair of the American Indian Studies at San Francisco State University, where he is an affiliated faculty member in Educational Leadership, Sexuality Studies and Race and Resistance Studies.**

**His forthcoming book, *Indian Blood: HIV and Colonial Trauma in San Francisco's Two-Spirit Community*. (University of Washington, May 2016), explores the efficacy of an Indigenous stress coping mechanism along with a new intervention model on Inter-Generational Healing and Cultural Leadership to reduce HIV risk among multiracial, two-spirit populations.**

By **Ben Wilcock**

### **Us Mob & HIV**

*Us Mob & HIV* is a new health promotion resource for Aboriginal and Torres Strait Islander communities, produced by the Australian Federation of AIDS Organisations (AFAO). The pocket-sized booklet aims to increase Aboriginal and Torres Strait Islander people's knowledge about HIV and its impacts.

*Us Mob & HIV* is the third edition of a resource originally published as *HIV and Us Mob*. Previous editions continue to remain in high demand, demonstrating a clear need to maintain availability of a core HIV resource for Aboriginal and Torres Strait Islander communities in a format that is culturally appropriate.

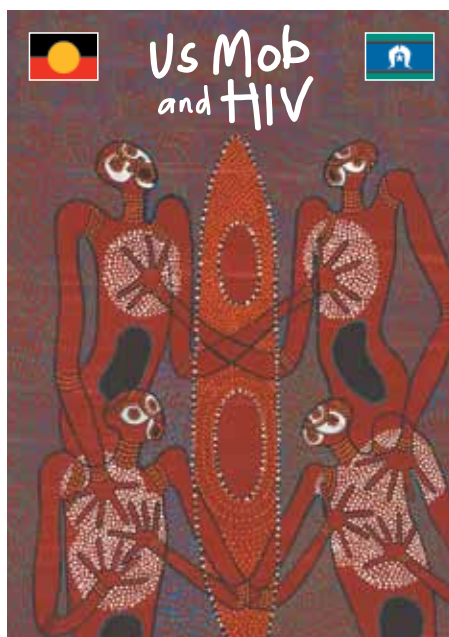
The booklet provides basic information on HIV, focusing on transmission, prevention, HIV testing, HIV treatments, health monitoring, care and support available for people with HIV, as well as service contact details. Information on HIV treatments, testing and other topics has been updated for the revised edition and importantly, it provides a clear explanation of the concept of undetectable viral load.

The booklet includes a series of 'yarns' written by community members, designed to reinforce and personalise key health messages. Information is also communicated in visual form, with artwork and illustrations by Indigenous artists Gary Dickinson and Arone Meeks. The personal stories and illustrations create a sense of community ownership and help to ensure that the content is seen as relevant and engaging.

Hard copies of the *Us Mob & HIV* booklet are available from AIDS Councils in each state and territory, and are being distributed to many service providers including Aboriginal Medical Services. A digital version of the booklet is available on the AFAO website.

### **Taking a Look**

Gay men and other men who have sex with men continue to be the group most



affected by HIV in Australia, with around three-quarters of new infections each year occurring among these men. Among Aboriginal and Torres Strait Islander communities, men who have sex with men account for just over half of all new HIV diagnoses.

As younger men become sexually active, and as some older men come out, there is an ongoing need to provide concise and clear advice about the fundamentals of HIV prevention and gay sex.

With this in mind, AFAO has produced a fully revised edition of its booklet *Taking a Look*, providing up-to-date information on all the basics of HIV prevention for gay and bisexual men. This new edition of the resource has also been produced as a website.

The booklet aims to increase health literacy among gay and other men who have sex with men about HIV. It includes information on HIV transmission and prevention, HIV testing and diagnosis, as well as information about how to prevent other sexually transmissible infections.

This second edition of *Taking a Look* features expanded information on range of options for HIV testing, prevention and treatment. Topics include information



about how often to get tested, links to information on where to get tested and what the experience of having an HIV test is like. It also contains information about pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP). The booklet is not targeted to any specific gay community, Indigenous or non-Indigenous. The new edition of *Us Mob & HIV* can be used as a complementary resource for health promotion among Aboriginal and Torres Strait Islander communities.

Hard copies of *Taking a Look* are available from AIDS Councils in each state and territory and are being distributed to many service providers. A digital version of the booklet is available on the AFAO website. The website version of the resource is available at: [takingalook.org.au](http://takingalook.org.au)

**Ben Wilcock is an HIV Health Promotion Officer at AFAO.**



## Colouring the Rainbow – Blak Queer and Trans Perspectives: Life Stories and Essays by First Nations People of Australia

Edited by Dino Hodge. Published by Wakefield Press, Adelaide.

Reviewed by **Gregory Phillips**

In this superb collection, twenty-two Aboriginal and Torres Strait Islander people share their stories in powerful accounts of identity, belonging, colonisation and liberation. The contributors identify as sistergirl, brotherboy, lesbian, gay and queer, and they are strong leaders, change agents, intellectuals, artists, survivors and sportspeople.

The tome is organised into three sections: life stories, public emergence, and academic analysis of the socio-political forces that impact on Aboriginal Queer realities.

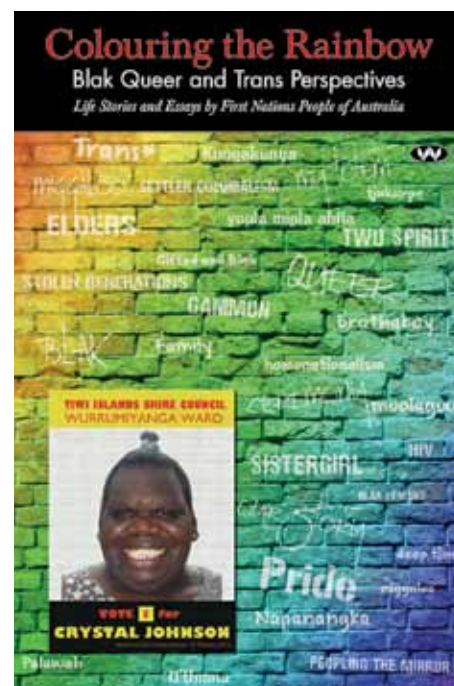
Crystal Johnson's life story is a perfect opening to the collection because her story illustrates how important it is for Aboriginal and Torres Strait Islander people to define and share their own cultural, sexual and gender belongings. As a sistergirl, her story illustrates how being Tiwi (Aboriginal), trans, Christian, an HIV educator and a keeper of traditional Tiwi knowledge can all exist at the same time in one Beautiful Blak body! Her self-meanings are what is powerful and piercing. While Kai Clancy, Ben Gertz and others' stories portray the real struggles involved in self-acceptance and dealing with bigotry, they are also stunning and sweet pictures of family acceptance, cultural mentorship, and pride in political activism.

The contributors in the second section on public emergence tell of raw strength, community action, and the beauty of working with communities in an empowering way. The late Rodney Junga-Williams', and Brett Mooney's, stories are perhaps particularly relevant to the readership of *HIV Australia*, because they confront HIV head-on as activists, educators and leaders. They break down barriers, open hearts and educate minds. All of the stories in this section represent a turning point in Aboriginal Queer lived realities. Far from being the tragic and romanticised people others sometimes want them to be, the contributors here are examples of brave hearts and true souls – not just because they overcome

the degradation that racism, sexism and heteronormativity seeks to impose on them in multiple and regular ways, but because they render colonisation and patriarchy starkly bare; exposing its guts and skin through sheer determination and the will to speak truth to power.

In finely honed analyses, the contributors in the third section point out that while Queer communities are also marginalised, the largely white, middle class, male keepers of power in Queer movements are often complicit in the ongoing colonial project. The writers suggest that liberation is not only about overcoming racism in the white community, homophobia and transphobia in Aboriginal communities, or sexism and heterosexism in both, but about revealing that the power relations of the colonial project are still alive today, and inform all of these forms of bigotry. Maddee Clark writes, 'Aboriginal sexual histories are often written by settlers with an anxious investment in believing that white settlement is justified, largely peaceful, and necessary' (p. 239). Importantly, Oscar Monaghan asserts that overcoming this legacy will require an intersection of Aboriginal and Queer activism, where white Queers support Aboriginal sovereignty, and Aboriginal movements continue to support sexual and gender diversity.

Essentially, each of the stories in this collection is saying that white views on what constitutes culture, sexuality, gender and tradition ought to be irrelevant to Aboriginal and Torres Strait Islander lived realities. While white society continues to attempt to define, shape and control Aboriginal and Torres Strait Islander peoples, especially in terms of the onslaught of HIV and other newer waves of mass trauma, these stories illustrate beautifully the power and groundedness of returning home. Returning to, or re-creating, one's cultural, familial, spiritual, social or political belongings – however self-defined – is an essential act for all humans. These leaders exemplify it.



A final note on editorship is necessary. As an Aboriginal Queer academic myself, I question why a non-Aboriginal man has come to edit such a powerful collection of stories. While there may have been invitations issued for him to do so, at the very least, co-editorship with Aboriginal editors could have been considered. Are some white academics taking up space, voice and editorial power that should and could be filled by Blackfullas? Should non-Aboriginal writers and editors step back and allow space for Aboriginal and Torres Strait Islander peoples to decide and edit what our own collections of stories look like? Yes. Otherwise, white power can get reinscribed in apparent acts of allegiance, demonstrating what contributors in this book call out.

That said, these twenty-two Blak Queer leaders, working with Dino Hodge, have delivered finely nuanced and powerful stories that the social, literary and cultural world desperately needs. They are all to be congratulated.

**Associate Professor Gregory Phillips, PhD, is a Research Fellow in Aboriginal Health at the Baker IDI Heart & Diabetes Institute.**

## ANTIRETROVIRAL TREATMENT USE, CO-MORBIDITIES AND CLINICAL OUTCOMES AMONG ABORIGINAL PARTICIPANTS IN THE AUSTRALIAN HIV OBSERVATIONAL DATABASE (AHOD)

David J. Templeton<sup>a,b,c\*</sup>, Stephen T. Wright<sup>a</sup>, Hamish McManus<sup>a</sup>, Chris Lawrence<sup>d</sup>, Darren B. Russell<sup>e,f,g</sup>, Matthew G. Law<sup>a</sup>, Kathy Petoumenos<sup>a</sup> and on behalf of the Australian HIV Observational Database

The rate of HIV diagnoses among Australian Aboriginal and Torres Strait Islander (hereafter 'Indigenous') people over the past decade has been similar to that among non-Indigenous Australians.<sup>1</sup> However, factors such as high rates of sexually transmitted infections (STIs), social disadvantage and poor access to health services may lead to an elevated risk of HIV infection<sup>2</sup>, as has been witnessed among Canada's Indigenous population<sup>3</sup>.

There are few published data regarding clinical outcomes and co-morbidities of Aboriginal Australians living with HIV and it is unknown if these differ from non-Indigenous HIV-positive Australians. Our aim was to describe demographic factors, clinical characteristics, and co-morbidities among Indigenous participants, and compare them with those of non-Indigenous participants enrolled in a large Australian clinical cohort of HIV-positive patients.

As far as we are aware, these are the first data comparing clinical outcomes between Indigenous and non-Indigenous HIV-positive Australians. The forty-two Indigenous participants represent over just under 10 % of all Indigenous Australians ever diagnosed with HIV. Although outcomes were not significantly different, Indigenous patients had lower rates of laboratory testing for HIV and lipid/glucose parameters. Given the elevated risk of cardiovascular disease in the general Indigenous community, the additional risk factor of HIV infection warrants further focus on modifiable risk factors to maximise life expectancy in this population.

The Australian HIV Observational Database (AHOD) commenced enrolment in 1999 and is a prospective

cohort of HIV-positive participants attending HIV outpatient services throughout Australia, of which 20 (74%) sites report Indigenous status. Data were collected up until March 2013 and compared between Indigenous and non-Indigenous participants. Person-year methods were used to compare death rates, rates of loss to follow-up and rates of laboratory testing during follow-up between Indigenous and non-Indigenous participants.

Virological suppression is currently considered the best measure of successful response to combination antiretroviral therapy (cART). Overall in AHOD more than 80% of treated participants are virologically suppressed in any calendar year over the last decade<sup>4</sup>, which is broadly similar to the rates of suppression with various cART regimens in other settings<sup>5,6,7</sup>. The two-year virological suppression rates after commencing cART in our substudy participants of around 80% irrespective of Indigenous status is encouraging, and is likely to reflect good engagement in care.

The significantly lower rate of testing for immunological, virological and other health parameters among Indigenous participants is of concern. The reasons for less frequent laboratory monitoring of Indigenous participants are unclear as such data are not captured in AHOD. However possible reasons could include economic or geographic challenges in accessing care. If such challenges exist for rural and remote Indigenous people living with HIV, formal programs providing social, financial and travel support to enhance HIV monitoring and care may be beneficial in maintaining their long-term health.

Clinical outcomes appear no worse among Indigenous participants enrolled in AHOD compared with their non-Indigenous counterparts. This may not be representative of the situation among Indigenous patients outside the study. It is likely, at least in part, to reflect engagement in HIV care, as enrolment in AHOD requires attendance at a clinical service providing HIV care. Nonetheless, other health outcomes, such as those among pregnant HIV-positive Indigenous women, have been shown to be equivalent to those among non-Indigenous patients<sup>8</sup>,

provided that comprehensive, culturally appropriate, multidisciplinary care is provided.

Indigenous patients in our large clinical cohort had lower rates of laboratory testing for HIV and lipid/glucose parameters than non-Indigenous participants. Overall, lipid and glucose testing among Indigenous participants occurred at under half the frequency that is recommended in national guidelines.<sup>9</sup>

At enrolment, the median age of Indigenous participants was younger than non-Indigenous participants but median time since HIV diagnosis was similar. Mean CD4 counts were also similar between Indigenous and non-Indigenous participants at enrolment to AHOD. Compared with non-Indigenous participants, a higher proportion of Indigenous participants were female ( $p=0.029$ ), living in non-metropolitan areas ( $p<0.001$ ), and reported potential HIV exposures of heterosexual contact ( $p=0.022$ ) and injecting drug use ( $p=0.082$ ). In addition, fewer Indigenous participants reported male-to-male sexual contact alone as their most likely HIV risk exposure ( $p=0.002$ ). Most participants, irrespective of Indigenous status, had an undetectable HIV viral load, and over 40% of both groups had a CD4 count of  $>500/\text{mm}^3$ . Similar proportions of Indigenous and non-Indigenous participants were currently infected with hepatitis B or had evidence of current or past hepatitis C infection.

Indigenous participants were tested significantly less often for HIV markers (CD4 count and HIV viral load), while testing rates of lipids and blood glucose among Indigenous participants were almost half that of non-Indigenous participants.

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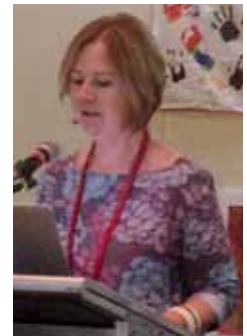
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## 21 years: renewing the call for government action on HIV and Aboriginal and Torres Strait Islander communities

By Linda Forbes

**On the final Day of Anwernekenhe 6, Linda Forbes, Policy and Communications Manager at AFAO, gave an address reflecting on the importance of Anwernekenhe's 21 years, the Anwernekenhe National HIV Alliance's (ANA) ongoing relationship with AFAO and its current funding situation.**



Firstly, I'm thrilled to be here and acknowledge the Arrernte people, past and present, of the land on which we meet today. I also acknowledge the Gadigal people of the Eora nation – the land on which the AFAO office in Sydney stands. I'm here to give you a rundown of the ANA's growth from birth, through its toddler days, the awkward teen years – some insights into what it's been like for AFAO to guide and support the ANA in its quest to become a fully independent community-based organisation.

I'd planned to be a tad funny today – maybe get a few laughs! But in writing this it's sadly clear to me that, while the ANA's story is great and something to be proud of, at the moment, the state of things at the federal level is just not a laughing matter.

You've all heard mention of AFAO over the last couple of days – tributes to Gary Lee's vision and passion at the very beginning; to AFAO's Indigenous project, managed by Tim Leach, that allowed AFAO to employ the absolutely amazing Michael Costello-Czok; AFAO's support and guidance during the development of the ANA towards incorporation; and AFAO's financial support, pending approval of AIDS Trust of Australia's funding, to sustain the ANA when Commonwealth funding has been withdrawn or delayed.

Well, how do we feel at AFAO? Well I must say we're proud – that despite a lack of commitment to secure, ongoing funding from successive federal governments, the ANA now has an equal place on the AFAO Board with the other national peaks representing people living with HIV and people in the communities most affected by HIV – the National Association of People Living With HIV Australia (NAPWA), AIVL (Australian Injecting and Illicit Drug Users League), and Scarlet Alliance, Australian Sex Workers Association. This means that the ANA now guides AFAO's work; the tables have turned.

The ANA has also provided input into the Commonwealth's strategies to address HIV and Aboriginal and Torres Strait Islander communities. The ANA was included in consultations to develop both the current *Fourth National Aboriginal and Torres Strait Islander Blood Borne Virus (BBV) and Sexually Transmissible Infections (STI) Strategy*, and its three predecessors. The current strategy and those before it include a commitment that the federal government sustain and build what's touted to be Australia's world-leading, model response to HIV – successes including keeping a lid on HIV rates in Indigenous communities, unlike comparable countries such as Canada.

Australia attributes its success in responding to HIV to its partnership approach that ensures the meaningful engagement of people living with HIV and affected communities – a partnership of governments, community organisations, clinicians – and researchers such as James Ward. The ANA's and the National Aboriginal Community Controlled Health Organisation's (NACCHO's) input means that the Commonwealth is able to say that non-government organisations representing Aboriginal and Torres Strait Islander communities have contributed to development of Australia's national BBV and STI strategies.

The national BBV and STI strategies were approved in July 2014 – just in time for the AIDS 2014 conference in Melbourne and the Indigenous pre-conference in Sydney. How embarrassing if Australia had had no national HIV strategies in place during AIDS 2014 conference and the International Indigenous Pre-conference, especially when we've been so proud of the fact that when the US launched its first national HIV strategy we were up to our sixth!

So, we have national strategies with actions to address HIV in Aboriginal and Torres Strait Islander communities – but something's missing? Where's the action? What's happening with implementing the strategies?

Well, they're in limbo – not yet approved 18 months into the life of the current national strategies.

Also in limbo is funding for the national HIV peaks. The ANA is by far the worst affected by this because it's so small and poorly funded anyway but we're all in limbo – AFAO, NAPWA, Scarlet and AIVL as well, with Department of Health funding contracts lapsing in either December 2015 or in June next year, and tenders either undecided or not yet called. Unsettling to put it mildly.

Despite all these character-building funding adventures – we're all here, celebrating 21 years of the Anwernekenhe. The ANA has struggled to grow and thrive – but here you all are – testament to its strength! What a privilege to be here and to see the wonderful film on the first conference 21 years ago. AFAO now relies on and depends on the ANA's input as an equal partner – and let's all remember that the Commonwealth does too.

So let's not feel too discouraged that the ANA has had ongoing funding struggles despite its contribution to the national strategies and to the international AIDS conferences in 2014. Instead, feel proud. These achievements constitute an enduring legacy for the ANA; Australia presented the ANA's strength and commitment to the world in 2014 and your community's growing strength, passion and resilience has shone through over the 21 years since the first Anwernekenhe conference.

Here's to the next 21 years!

Linda Forbes is Policy and Communications Manager at AFAO.

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