



# HIV AUSTRALIA

**Respect and resilience:  
shaping the response to HIV  
and STIs among Aboriginal and  
Torres Strait Island communities**

Volume 11 • Number 3



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## Editorial

**We acknowledge traditional owners and custodians of land, Elders both past and present, and acknowledge the tremendous part you have all played in keeping communities strong, resilient and engaged in this important area of work. It was over 20 years ago when alarm bells were sounded about the devastating impact that HIV/AIDS could have on our communities. This hasn't happened, so thank you!**

We would also like to acknowledge the leaders, the pioneers of HIV/AIDS in Aboriginal and Torres Strait Island communities – those who have left us and those who continue to advocate and positively influence the policy and program agenda. There are far too many to mention here, but we pay our sincerest respects to you, your families and friends. Thank you!

This edition of *HIV Australia* focuses in on Aboriginal and Torres Strait Islander HIV, sexual health and related issues for many reasons. Like many areas of Aboriginal and Torres Strait Islander health, there is a disproportionate rate of morbidity associated with many sexually transmissible infections (STIs), HIV, and other blood borne viruses compared to non-Indigenous Australians. This area is complex to explain, it is sensitive, it is often classified as men's or women's business, it is about people's personal lives, their behaviours (both hidden and open); but most importantly, this disparity is a symptom of both historical and contemporary issues impacting on Indigenous Australians. In a contemporary and health setting environment STIs, HIV and viral hepatitis compete with a raft of other health priorities such as chronic disease, child and maternal health, grief, loss and trauma.

The risk factors for HIV are there – they are visible, but often they are difficult to address. These include individual behaviours, and societal and structural factors such as environment, employment, economic opportunities, education outcomes – and for many – poverty. In addition, the magnitude of intergenerational trauma arising from previous policies and programs is an area not well understood in Australia but known to impact on other Indigenous populations globally, particularly in the area of HIV.

This edition of *HIV Australia* explores some of the work underway in Australia to address rates of STIs and HIV in the fields of prevention, clinical care, epidemiology and public health. New technology is discussed, both in the use of point-of-care devices to test and diagnose in clinics, particularly in communities where endemic rates of STIs exist, and in disseminating health promotion messages to young Aboriginal people through digital and social media as well as through artistic expression. Authors explore the impact of HIV, STIs and other BBVs affecting Aboriginal and Torres Strait Island communities, addressing cultural and societal experiences. Several articles discuss health promotion programs and other programs using a community development approach. Contributors also discuss the myriad of related challenges facing a diverse community.

We hope you enjoy this edition of *HIV Australia*. We hope to have highlighted some of the programs underway in Australia to address this often neglected area of Aboriginal and Torres Strait Islander health. In the next year, Australia will host the International AIDS Conference – the world's largest medical event. This will be held in Melbourne in July and immediately prior to this an Indigenous peoples pre-conference meeting will be held in Sydney, bringing international and national delegates together to discuss responses, advocacy issues, research and programs, as well as to participate in an exciting social and cultural program. We look forward to your participation in both events.

This is a timely edition of *HIV Australia* as we head into 2014. Much more work needs to be done to ensure equitable health care and outcomes for our mob, and we will continue on the path of rectifying this into the future. Stay strong, healthy and resilient.

Thank you to all who have contributed to this edition, particularly Arone Meeks for the beautiful artwork and Neville Fazulla for sharing his personal story, both inspirational men. Finally, this edition wouldn't have occurred if not for the very hard work of Finn O'Keefe and Linda Forbes at AFAO; thank you so much for keeping us on track and producing such a great edition.

Sincerely, James Ward and Michael Costello



**James Ward** is an Indigenous health researcher with more than 15 years' experience. He is a descendent of the Pitjantjatjara and Nurrunga clans of central and South Australia.



**Michael Costello** has over 18 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) acknowledges the traditional owners of the lands we operate on across Australia. AFAO pays tribute to Indigenous Elders past and present – particularly to the Elders who have assisted in producing this edition of *HIV Australia*. We also pay tribute to community members who have so generously participated in the research described in this magazine.

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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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**Cover artwork:**  
Arone Meeks, *Freshwater/Saltwater*,  
mixed media on Arches paper, 2012,  
760 x 560 mm

<p><b>What's happening for young Aboriginal and Torres Strait Islander people in relation to health service access, risk behaviours and knowledge of sexually transmissible infections and blood borne viruses: findings from the GOANNA study</b> by James Ward, Joanne Bryant, Heather Worth, John Kaldor, Dea Delaney-Thiele, Marian Pitts, Dy Kelaart, Elizabeth Moore, Sallie Cairnduff, Sidney Williams, Peter Waples-Crowe, Kat Byron, Andrew Bamblett, Sarah Betts and Tony Coburn on behalf of the GOANNA study team</p> <p><b>More work is required to reduce sexually transmissible infections in Aboriginal and Torres Strait Islander communities</b> by James Ward, Andrew Nakhla, Melanie Middleton, Ann McDonald and Rebecca Guy</p> <p><b>STRIVE: making a difference for sexual health in remote Aboriginal communities</b> by John Kaldor, James Ward, Rebecca Guy and Alice Rumbold on behalf of the STRIVE team</p> <p><b>Living positively: Neville's story</b> by Neville Fazulla</p> <p><b>The Anwernekenhe journey</b> by Michael Costello</p> <p><b>Our Destiny Haz Arrived: a national HIV prevention and testing campaign for Aboriginal and Torres Strait Islander gay men and sistergirls</b> by Michael Costello</p> <p><b>Promoting Aboriginal and Torres Strait Islander gay men and sistergirl sexual health in Queensland: The 2 Spirits program</b> by Michael Scott</p> <p><b>Us mob: gar'ban'djee'lum network</b> by Dion Tatow</p> <p><b>PATSIN: the Positive Aboriginal and Torres Strait Islander Network</b> by Ian Saunders</p> <p><b>Ngalawi Djardi 'Sit &amp; Yarn': ACON Health Retreat for Aboriginal and Torres Strait Islander People Living with HIV</b> ACON reports on its successful retreat program</p> <p><b>Celebrating strength: the role of resilience in responding to blood borne viruses and sexually transmitted infections among Indigenous communities</b> by Maurice Shipp, Edward Wilkes, John Kaldor and Dennis Gray</p> <p><b>Live deadly stronger and longer: Ask for a Test</b> by the Northern Territory AIDS and Hepatitis Council</p>	<p>4</p> <p>7</p> <p>10</p> <p>13</p> <p>16</p> <p>18</p> <p>20</p> <p>24</p> <p>25</p> <p>26</p> <p>27</p> <p>30</p>	<p><b>The management of people with HIV who place others at risk (POAR): implications for Aboriginal and Torres Strait Islander people</b> by Natasha Pavlin</p> <p><b>HIV risk practices among Indigenous Australian and Anglo-Australian gay and bisexual men</b> by Toby Lea and Martin Holt</p> <p><b>Findings from the Queensland Injecting Drug Survey (QuIDS): comparing hepatitis C risk behaviours among Indigenous and non-Indigenous people who inject drugs</b> by Abhilash Dev, Robert Kemp, James Ward, Suzanna Henderson, Sidney Williams, Andrew Smirnov, Maria Plotnikova and Jake M Najman</p> <p><b>Stigma and discrimination won't bring us down!</b> by the Scarlet Alliance Aboriginal and Torres Strait Islander Inclusion Working Party</p> <p><b>Think About the Choices You Make: creating a culturally appropriate sexual health promotion DVD for young Aboriginal people</b> by Laura Jenkins, Marnie Britton, Kate Green, Christine Edwards, Graham Smith, Karen Nairn and Karen Gillham</p> <p><b>Connecting with youth: how arts-based health campaigns are engaging young Aboriginal people in NSW</b> by Matthew Rodgers</p> <p><b>Mind The Gap: addressing HIV and STIs among young people in rural and regional areas</b> by Ann-Marie Roberts</p> <p><b>What is the role of HIV and STI point-of-care tests in remote Aboriginal and Torres Strait Islander communities?</b> by James Ward, Lisa Natoli, Louise Causer, John Kaldor and Rebecca Guy on behalf of the TTANGO Investigator Team</p> <p><b>Treatment as prevention: what's required to make this a relevant strategy in Aboriginal and Torres Strait Islander communities?</b> by James Ward</p> <p><b>Regional Feature: Nothing about us without us! HIV and Indigenous peoples</b> by Marama Pala (Ngatiawa Iwi)</p> <p><b>Book review: Condoman and Lubelicious</b> Reviewed by Neville Fazulla</p> <p><b>Treatment briefs</b></p> <p><b>Conferences</b></p>	<p>32</p> <p>35</p> <p>37</p> <p>41</p> <p>43</p> <p>46</p> <p>49</p> <p>51</p> <p>55</p> <p>57</p> <p>60</p> <p>61</p> <p>63</p>
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Throughout this edition of *HIV Australia* we feature a selection of artworks by internationally-renowned artist Arone Meeks. Arone is a Kuku Midigi man, whose country is the area around Laura, Cape York. His work celebrates themes including country, nature, spirituality and sexuality.

Arone completed a Bachelor of Visual Arts at Sydney's City Art Institute in 1984. His artistic practice is informed by the teachings of his grandfather and other relatives, as well as study he undertook with various tribal Elders, including those of the Lardil people of Mornington Island. 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. Arone is also a mentor in visual arts and regularly conducts workshops with remote Indigenous communities. He is also a Health Promotion Officer with the 2 Spirits program in Queensland.

*HIV Australia* is delighted to be able to feature Arone's beautiful artwork in this edition.





## What's happening for young Aboriginal and Torres Strait Islander people in relation to health service access, risk behaviours and knowledge of sexually transmissible infections and blood borne viruses: findings from the GOANNA study

By James Ward, Joanne Bryant, Heather Worth, John Kaldor, Dea Delaney-Thiele, Marian Pitts, Dy Kelaart, Elizabeth Moore, Sallie Cairnduff, Sidney Williams, Peter Waples-Crowe, Kat Byron, Andrew Bamblett, Sarah Betts and Tony Coburn on behalf of the GOANNA study team.

### Introduction

Aboriginal and Torres Strait Islander young people are a priority population in all national and jurisdictional sexually transmissible infection (STI) and blood borne virus (BBV) strategies, but until recently we have had little information on which to build and evaluate responses. This situation has changed radically in the past two years, with the implementation of the GOANNA study.

GOANNA is the first national survey of Aboriginal and Torres Strait Islander

people aged 16–29 in relation to sexually transmitted infections and blood borne viruses, with an emphasis on young people's levels of knowledge, risk behaviours and health service utilisation. The survey was initiated because Aboriginal and Torres Strait Islander people are particularly disadvantaged with regard to STIs and BBVs – these being major causes of ill health, as well as substantial contributors to personal distress and relationship breakdown. Across Australia, cases of these infections are far more frequently diagnosed among

Aboriginal and Torres Strait Islander young people than among their non-Indigenous counterparts<sup>1</sup>, and despite a long history of providing programs and policies aimed at preventing STIs and BBVs in Aboriginal and Torres Strait Islander populations, there has so far been limited change in their prevalence or incidence, apart from in a few areas<sup>2</sup>.

To address this we undertook a national cross-sectional survey asking young Aboriginal and Torres Strait Islander people (aged 16–29) questions about

knowledge, risk behaviour and health service utilisation. This article discusses the survey findings related to STI and HIV risk behaviour, knowledge and health service access.

### Survey method

The survey used methods originally developed through a collaborative project between the Aboriginal and Health and Medical Research Council of NSW and the former National Centre in HIV Social Research (now known as Centre for Social Research in Health) based at the University of New South Wales.<sup>3,4</sup> The methodology was then extended to all jurisdictions, with the support of an ARC Linkage Grant involving partners from both government and the community-controlled sector.

Recognising that conventional sample approaches such as household or schools-based sampling were unlikely to yield representative samples of this population, Aboriginal and Torres Strait Islander cultural and sporting events were considered ideal occasions that provided an opportunity to sample a random cross section of young people. Sampling from community events has been used with other hard-to-reach populations in Australia, such as men who have sex with men (MSM) in the Gay Community Periodic Surveys, with a demonstrated capacity to monitor risk practices over time.<sup>5</sup> Events where surveys were administered included Australia Day/Survival Day events, Aboriginal State and Territory sports carnivals, spirit and cultural events, and NAIDOC week (the National Aborigines and Islanders Day Observance Committee) events.

In order to ensure self-determination in this research, Aboriginal organisations and staff were engaged at every level of the project.

### Administering the survey

Surveys were collected using portable handheld Personal Digital Assistants (PDAs) or hand held computers. The PDAs were loaded with a specialised program to administer the prepared questionnaire and collect information in a de-identified, secure format. Participants were expected to read the questions and provide their responses by touching the screen with a small stylus.

Audio recordings of the questionnaire were also available to the participants from the device. The audio recordings were in English, with a choice of either a male or female voice to ensure gender acceptability. Audio recordings translated in local Aboriginal languages were also trialled on the device at selected locations.

The project was administered by State and Territory National Aboriginal Community Controlled Health Organisation (NACCHO) Affiliate organisations. Each affiliate was asked to nominate a key person to drive the project. It was this person's responsibility to nominate events in their jurisdiction where the survey could be administered. These individuals were also responsible for recruiting and training survey collection staff, liaising with events managers and administering, collecting and storing data from the PDAs. Capacity building was a key component of the project; at all stages it was our desire to engage young Aboriginal people in the research collection process.

Over two years, the survey was implemented at 40 events across all eight jurisdictions. A total of 2,877 young people participated: the median age was 21 and 60% were female. Around half the participants were residents in major cities, 36% were from regional centres, and 9% were from remote areas. 57% of respondents were single at time of participation, and of those in a relationship, 53% reported their partner to be Aboriginal and/or Torres Strait Islander. A series of questions pertaining to HIV and other STI transmission and risk were asked to gauge participants' understanding and levels of knowledge about these topics.

### Survey findings

Participant scores on each of the knowledge questions were aggregated to form a composite knowledge scale, with scale scores ranging from 0–12. A score of 12 corresponded to all questions answered correctly. The overall mean composite score for knowledge was 9.1. Mean scores were lower in the younger age groups; 8.5 for 16–19 year olds compared with 9.9 in the oldest age group 25–29. Men had a lower mean score overall than women; 8.8 compared with 9.3. Despite having good knowledge overall, participants reported

poorer knowledge about chlamydia (particularly in relation to its effect on pregnancy) and hepatitis B transmission.

Overall, the average age of sexual debut was 15 years of age. 67% of participants aged 16–19 reported previous vaginal sex, compared with 87% and 93% of people aged 20–24 and 25–29 respectively. 46% of respondents reported only one sexual partner in the previous 12 months. The majority of respondents reported having sex with similar aged partners; for example, 74% of 16–19 year olds reported having had sex with people aged 16–19. Men aged 16–29 reported having sex with someone they had just met at double the rate reported by women (20% vs 9%).



Arone Meeks' artwork (detail) created for World AIDS Day 2011.



Condom use was reported by many people aged 16–19, with 50% stating they always used a condom in the last year compared with 26% of people aged 25–29. Condom use at last sex did not vary between urban and remote communities. A third of all men reported being drunk or high at last sexual encounter compared to 22% of women aged 16–29. Overall, 41% of respondents reported that they had been tested for STIs in the last year (men 39%, women 44%).

People aged 16–19 reported lower STI testing rates in the last year than for people aged 20–24 and 25–29. Of those that had been tested, Aboriginal medical services were the most common place where STI testing occurred (55%), followed by private general practice (34%). Overall, 30% of respondents reported they had been tested for HIV. In total, 55% of respondents reported having an adult health check in the last year. Aboriginal Medical Services were reported by participants as the best way to seek help for STI/ BBV advice (58%) and for alcohol and other drug issues (51%).

## Conclusions

This data provides baseline information from young Aboriginal and Torres Strait Islander people about levels of knowledge, risk behaviours and health service access. Levels of knowledge were lowest for the youngest age groups, in particular men and for residents in more remote areas.

Greater efforts are required to ensure safe sex and sexual health information is appropriate and accessible for young people, particularly young men. Importantly, this includes providing information translated into local Aboriginal languages in communities where English is not the primary spoken language.

This data also provides compelling information about where targeted interventions are needed, particularly where efforts should be made to improve information and reduce risk practice among young men. Health service access for young Aboriginal and Torres Strait Islander people appears reasonable. Testing for both STIs and HIV are lowest for the 16–19 year old age group. Men attend testing less frequently and report lower testing rates, compared with women. Strategies to address men's health



GOANNA survey collectors. Photo: Attributes to the photographer.

are required, as are strategies to ensure testing occurs more frequently when people aged 16–29 attend health services.

Through this study we have collected data that will enable us to identify behavioural, demographic and access correlates of STI and BBV risk and other key outcomes. It has set the foundation for repeatable and ongoing rounds of surveys to assess changes and trends over time in these areas, much as the Gay Periodic Surveys have done for MSM over many years.

The GOANNA project provides evidence to shape policy and programs in this area and contribute to the broader body of knowledge in the area of Aboriginal and Torres Strait Islander sexual and blood borne virus health. It also places young Aboriginal and Torres Strait Islander people in a good position to answer questions related to the types of policy and programs that should be rolled out in communities, as well as opportunities to counter stereotyping of young people as often reported in mainstream media in Australia.

**Further information about the GOANNA study can be obtained from James Ward, Deputy Director, Baker IDI, Central Australia, Alice Springs.**

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# More work is required to reduce sexually transmissible infections in Aboriginal and Torres Strait Islander communities

By James Ward<sup>1,2</sup>, Andrew Nakhla<sup>1</sup>, Melanie Middleton<sup>1</sup>, Ann McDonald<sup>1</sup> and Rebecca Guy<sup>1</sup>

<sup>1</sup>The Kirby Institute, University of New South Wales, Sydney, Australia; and <sup>2</sup>Baker IDI, Central Australia, Alice Springs, Australia

## Summary

Australia's Aboriginal and Torres Strait Islander population continues to be overrepresented in notifications of sexually transmissible infections (STIs) while at the same time maintaining a stable epidemic of HIV. In particular, outer regional and remote communities continue to experience substantially higher rates of STIs. This article details surveillance data related to STIs and HIV recorded for Aboriginal and Torres Strait Islander communities for the period 1 January–31 December 2012.

## Chlamydia

Chlamydia continued to be the most frequently reported condition in Australia with 82,707 notifications in 2012. Of these, 6,792 (8%) were among the Aboriginal and Torres Strait Islander population, 34,762 cases (42%) were among the non-Indigenous population; and for 41,153 (49%) diagnoses, Indigenous status was not reported. The chlamydia notification rate in the Aboriginal and Torres Strait Islander population was four times higher than the rate in the non-Indigenous population.

Chlamydia predominantly affects people aged 15–29, with the highest notification rates occurring among women in the 15–29 year age group. This may reflect greater disease burden, and/or higher rates of access to health services and subsequent testing in these populations. Despite just 25% of the Aboriginal and Torres Strait Islander population residing in remote areas, chlamydia notifications reported from these areas accounted for 55% of all notifications in the Aboriginal and Torres Strait Islander population.

## Gonorrhoea

Of 13,649 notifications of gonorrhoea in 2012, 3,904 (28%) were among the Aboriginal and Torres Strait Islander population, 4,930 (36%) were among the non-Indigenous population; for 4,815

(35%) notifications, Indigenous status was not reported. The rate of gonorrhoea notifications in the Aboriginal and Torres Strait Islander population in 2012 was 21 times higher than in the non-Indigenous population. 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 which requires separate responses.

## Infectious syphilis

Nationally, 1,534 cases of infectious syphilis were diagnosed in 2012; 167 (10%) among the Aboriginal and Torres Strait Islander population, 1,257 (81%) among the non-Indigenous population and Indigenous status was not reported for 110 (7%) diagnoses. The notification rate of infectious syphilis in the Aboriginal and Torres Strait Islander population in 2012 was five times higher than the rate in the non-Indigenous population.

In 2012, the infectious syphilis notification rate in the Aboriginal and Torres Strait Islander population was higher in all age groups than the non-Indigenous population, particularly the 15–19 year age group where the rate of diagnosis was 40 times higher.

Like gonorrhoea, infectious syphilis affects two main population groups: young Aboriginal and Torres Strait Islander women and men in remote communities, and gay men living in major cities.

After an increase in the notification rate of infectious syphilis in the Aboriginal and Torres Strait Islander population in 2010–2011, which was attributed to an outbreak of syphilis in a few Queensland remote communities, the notification rate of infectious syphilis declined slightly in 2012. However, the trends vary across

jurisdictions, with a substantial decline in Northern Territory and a plateau in notifications in the Aboriginal and Torres Strait Islander population in Queensland.

## Donovanosis

There have been some successes in the control of STIs in remote Aboriginal communities – for instance the elimination of donovanosis from Australia is on track, with no cases detected in Australia in 2011 and only one in 2012 after a peak in the late 1990s and early 2000s.

## HIV

There were a total of 1,253 notifications of newly diagnosed HIV infection in 2012; 32 diagnoses were among the Aboriginal and Torres Strait Islander population. 225 cases of HIV infection were newly diagnosed in the Aboriginal and Torres Strait Islander population in the ten years from 2003 to 2012. Unlike the STIs mentioned previously in 2012, the notification rate of new HIV diagnosis in the Aboriginal and Torres Strait Islander population (5.5 per 100,000) was similar to that in the non-Indigenous population (excluding people from a high HIV prevalence country of birth) (5.1 per 100 000).

Among notifications of newly diagnosed HIV infection in 2008–2012, the most frequently reported route of HIV transmission was sexual contact between males in both the Aboriginal and Torres Strait Islander (56%) and non-Indigenous population (72%). A higher proportion of notifications from the Aboriginal and Torres Strait Islander populations were attributed to injecting drug use (13% vs 2%) and a similar proportion to heterosexual contact (18% vs 17%) compared with the non-Indigenous population.

This most recent data relating to Aboriginal and Torres Strait Islander people highlights the gaps that exist in health disparity in this area.

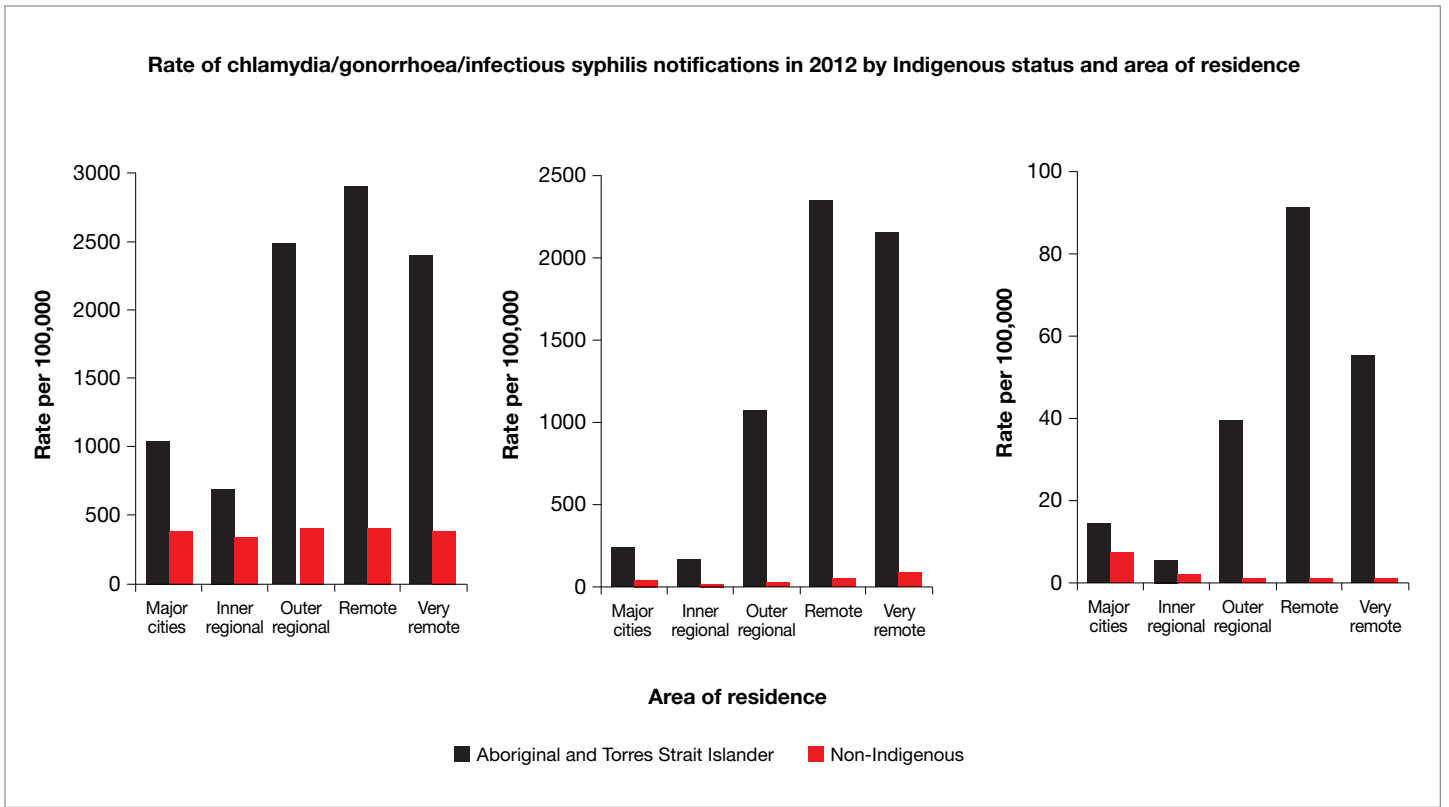


Figure 1

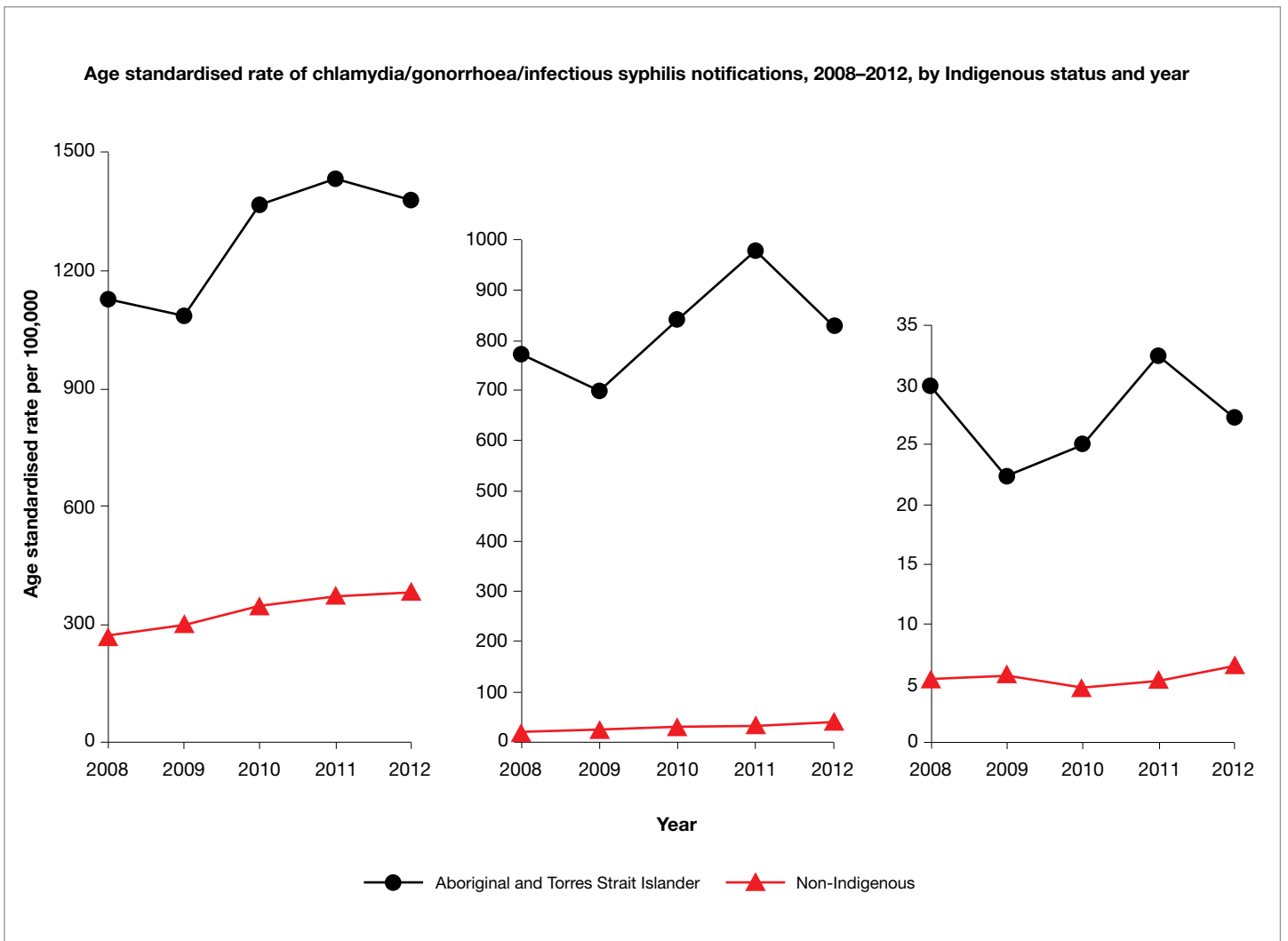


Figure 2



## Summary: implications for Aboriginal and Torres Strait Islander communities

Rates of STIs are particularly high among both Indigenous and non-Indigenous young people living in regional and remote areas of Australia; however, it is important to note that rates of chlamydia notifications are higher across all Aboriginal and Torres Strait Islander communities compared to the non-Indigenous population. Improving awareness of chlamydia is required at both community and clinical levels.

Internationally, high rates of STIs in communities are implicated in higher HIV notifications but this is not currently the case in Australia, where rates of HIV diagnoses among the Indigenous population are comparable to the non-Indigenous population.

STIs can also have significant physical, psychological and social consequences for those affected. 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. To achieve this further efforts are required in the following areas:

- Education and health promotion in school and teenage years;
- Effective clinical service delivery;
- Effective prevention strategies are in place across all communities.

Some work is underway in these areas (see pages 10 and 51 for two examples of current trials being conducted in remote Aboriginal communities), but more work is required across all remote and regional communities.

For further information, see the *2013 Aboriginal Surveillance Report of HIV, viral hepatitis, STIs* available at <http://www.kirby.unsw.edu.au>

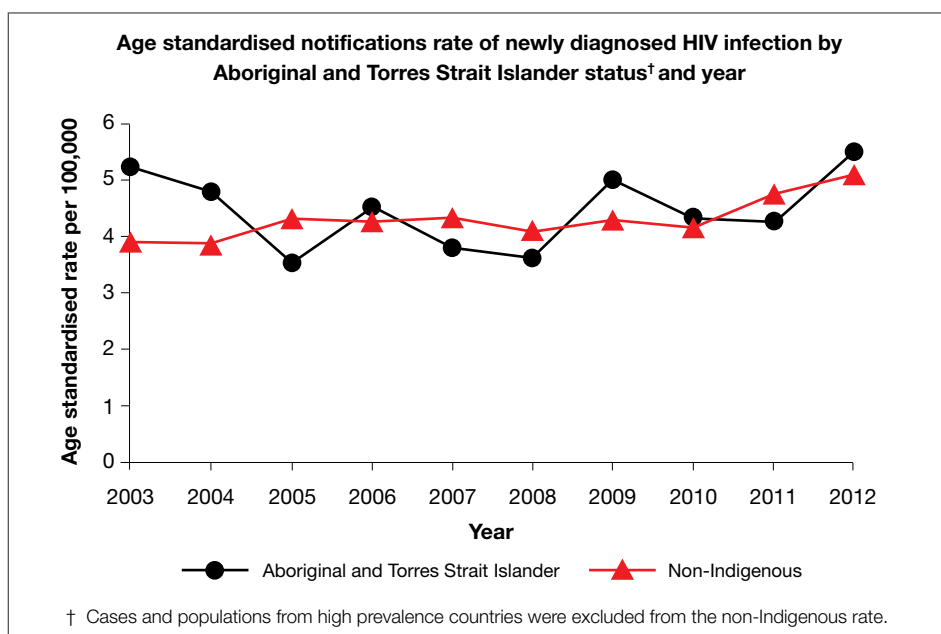


Figure 3

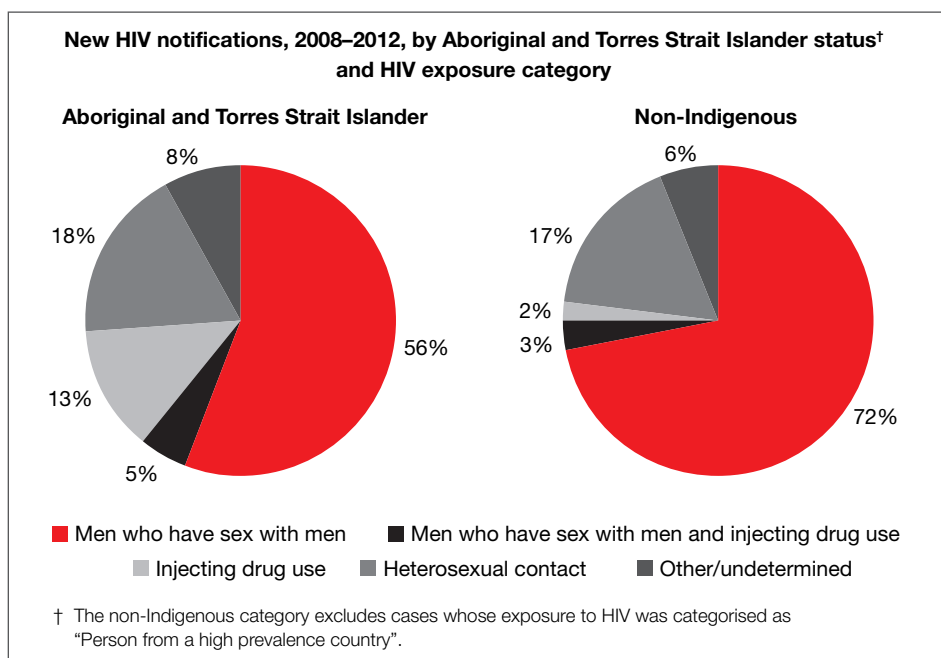


Figure 4

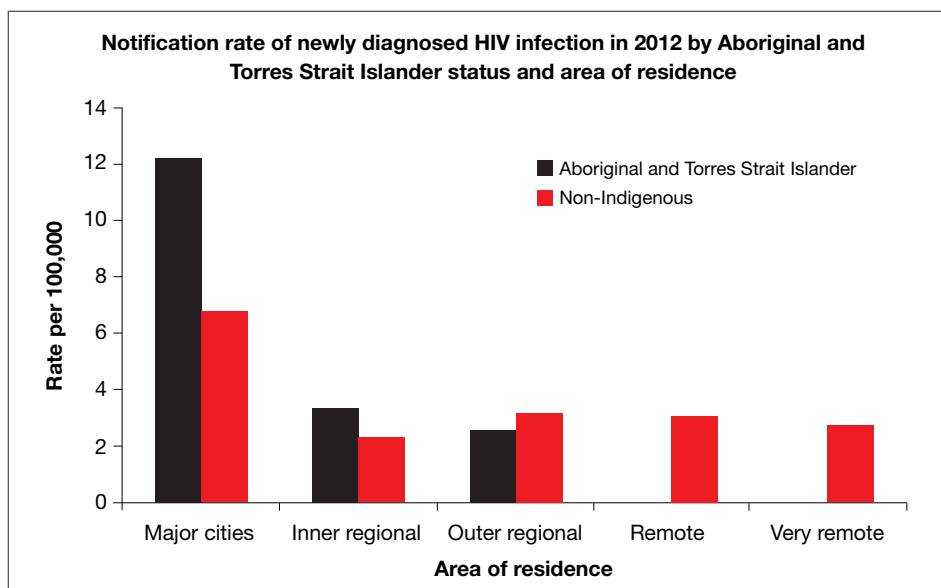


Figure 5

# STRIVE: making a difference for sexual health in remote Aboriginal communities

By John Kaldor, James Ward, Rebecca Guy and Alice Rumbold on behalf of the STRIVE team<sup>1</sup>

There is an urgency in Australia's response in addressing the high levels of curable sexually transmissible infections (STIs) that have been present in many Aboriginal and Torres Strait Islander communities for as long as records have been kept. The STRIVE trial in central and northern Australia, although still more than a year from completion, has already made important contributions to understanding what's required to bring down rates of these infections and their many adverse social and health consequences, particularly for young people.

## Common STIs in remote communities

The most common curable STIs in Aboriginal remote communities are gonorrhoea, chlamydia and trichomonas; in some remote communities over a third of adolescents and young adults have at least one of these infections. Although often asymptomatic, these STIs can nonetheless cause long-term harm if not treated – particularly among women, where they can damage the reproductive tract, leading to infertility or adverse pregnancy outcomes.



Arone Meeks' artwork (detail) created for World AIDS Day 2011.

These infections are all easily diagnosed with accurate tests, and curable with single dose antibiotics – strategies which have been available since the 1990s, and have formed the basis for policy and guidelines ever since. Apart from their direct impact, these infections are also known to increase the risk of HIV transmission – which has so far remained very rare in remote communities. This is in contrast to many other parts of the world, where HIV infection has moved rapidly into settings with high rates of other STIs.

Despite the policy emphasis on testing and treatment for curable STIs, few communities have seen a decline in the rates of these STIs since these strategies became available. There have been some notable exceptions, including the Anangu Pitjantjatjara Yankunytjatjara lands of northern South Australia, where sustained annual rounds of community-wide screening have led to falls in chlamydia and gonorrhoea prevalence; and the Tiwi Islands, where an intensive effort involving community and clinical leadership led to high levels of testing and treatment and, ultimately, falls in prevalence of these infections.

## Missed opportunities

Primary health services in many remote communities are faced with particular challenges in ensuring that testing for curable STIs is routinely offered to young people and that positive diagnoses are followed up according to guidelines, which include contact tracing and a repeat test at three months. An issue with guideline compliance has been the relatively low priority that is assigned to sexual health service delivery by some clinicians. Explanations for the low level of priority include the other competing demands of remote primary care, lack of training, and sensitivity about discussing sexual health with clients, particularly those of the opposite gender.

The STRIVE trial was conceived as a response to these concerns. The idea was that young people in remote communities

were coming to clinics, but that many opportunities were being missed to offer testing. If a framework of quality improvement for sexual health service delivery could be widely adopted, the result could be a general increase in the uptake of testing and appropriate follow-up for positive diagnoses. It was proposed that a cluster randomised trial design was needed to evaluate the strategy, first of all to ensure that necessary data could be collected; second to assess whether the strategies put in place to support quality improvement had an effect across a diverse range of services; and finally to provide a mechanism for detecting any changes in prevalence that might result from the quality improvement.

## Trial development

In early 2008, a workshop was held in Alice Springs to discuss the trial proposal. Representatives from government and community organisations came together to talk about the challenges of sexual health service delivery, and about what kind of research projects might be both feasible and useful. The meeting left many questions unanswered, but provided valuable insights into the requirements of services if they were to join a large-scale research project of this kind.

The submission for funding to support a large-scale trial in the Northern Territory went to the National Health and Medical Research Council, and an award of over \$1.7m was made in late 2008. There was immediate interest from health services in Western Australia and Queensland, so plans were modified to include the Kimberley region and Cape York.

A long series of consultations with government and community controlled health services began and extended over the next 18 months, and governance structures were established for the trial. Ultimately, participation agreements were signed that committed clinical services to involvement in the trial in some 68 remote communities, grouped by geographic and linguistic proximity into



24 clusters. The clusters were randomly assigned into three annual groupings; the first group of clusters to begin the quality improvement support process was initiated in early 2011. The third and last group joined in during the course of 2013, by which time all communities were in the 'active' arm of the trial.

### Trial operations

Once a clinic is assigned to the active arm of STRIVE, one of the regional coordinators for the project visits the clinic to conduct a 'systems assessment'. This process is undertaken with clinic staff and management, and involves developing a comprehensive description of the current status of sexual health service delivery at the clinic, under a number of key headings. Based on this assessment, and the area(s) identified in which there is room for improvement, the coordinator and clinic personnel develop an action plan aimed at addressing these areas. Whenever possible, the systems assessment visit also involves jurisdictional level personnel who are responsible for providing support to services in sexual health, or in related areas such as quality improvement.

The coordinator also provides the service with a report on its recent sexual health service activity in the areas of testing coverage in the target age groups, as well as other key indicators of clinical quality in sexual health. This initial report provides a baseline against which progress against key outcomes can be assessed by clinics as they implement the sexual health actions plan. Subsequently, the coordinators provide the services with regular reports against a number of sexual health service indicators, and regularly check in with services to see how they are progressing with their action plans and whether further technical assistance is required.

### Outcomes and achievements to date

A key development that was essential to the implementation of quality improvement was the upgrading of information systems at the participating clinics. Although virtually all clinics had computerised systems in place, there was not a standardised clinical template for recording sexual health-related encounters, and no easy way to obtain data on the services' activity levels in this area. To address this, templates and reporting procedures were developed, to

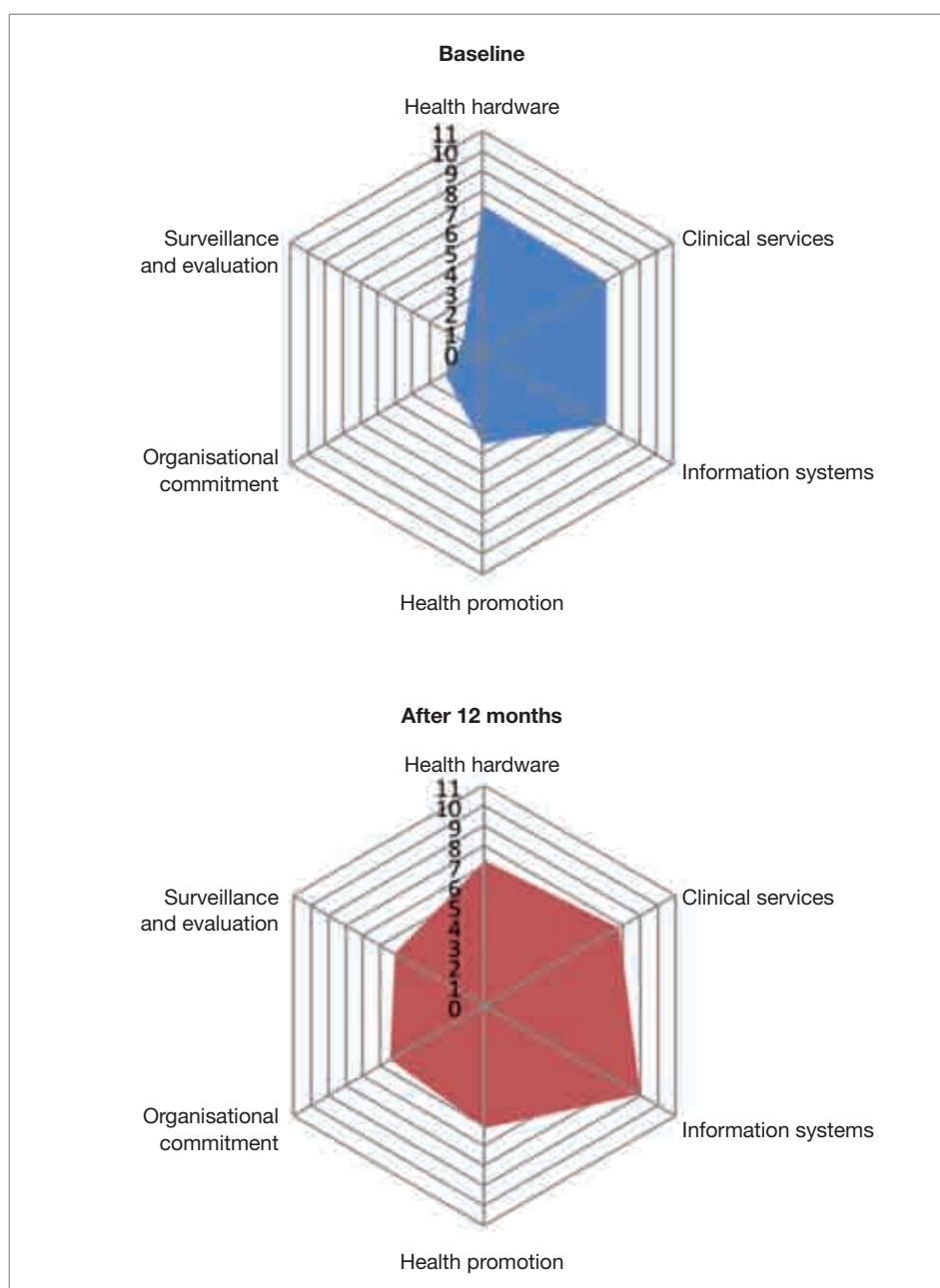


Figure 1

be integrated into the software systems at participating clinics. At the time of writing, some work remains to be completed on these developments, but the goal of having purpose built software to support clinicians in optimising sexual health clinical activities is now clearly in view. Many clinicians at primary care services participating in STRIVE have adopted regular use of the templates, and many services are receiving, scrutinising and acting upon regular reports on service activity.

Another major contribution that STRIVE has made, long before final results are available, is that it provides the first comprehensive epidemiological analyses of the occurrence of gonorrhoea, chlamydia and trichomonas among

Aboriginal people in remote communities. With tests in over 3,000 people available for analysis in baseline data collection, STRIVE has been able to provide an insight into geographic variations, the level and predictors of co-infections with multiple STIs, and the incidence of all three infections. This is the first time that these data have been available. Striking findings were the extremely high rates of infection, both incidence and prevalence, among young people (aged 16–24); the age and sex specific patterns of trichomonas (which had never been reported before), and the co-infection patterns. We have also been able to determine levels of HIV testing, and assess the extent of adherence to guidelines that HIV testing should be

offered to anyone with a positive STI result. On the basis of our preliminary results, it does appear that such testing is taking place quite consistently in many communities.

### Future challenges

In the final year of the trial, the task that now lies ahead for STRIVE is to see how effective quality improvement measures have been in increasing the rates of testing in young people, and ultimately in driving down community prevalence of these insidious STIs. Preliminary analyses of findings from the services that were randomised to quality improvement in the first year show improvements in the self-assessment by clinics of their capacity to deliver sexual health services (see Figure). These changes, across several domains of service activity, need to be assessed against the control clinics, but give some indication that the quality improvement activities have had an impact.

The STRIVE investigators have recently joined forces with researchers involved in

quality improvement in other areas of primary health care, and were successful in an application for a National Health and Medical Research Council (NHMRC) Partnership Grant, with the Northern Territory government and the Aboriginal Medical Services Alliance of the Northern Territory as the partners. This new five-year funding, under the name STRIVEplus, will enable investigators to track the long-term outcome of quality improvement activities, as well as identify the health service factors that are associated with successful improvement. The project will also determine the extent to which sexual health quality improvement encourages or impedes improvement in other areas of primary care.

By the end of next year, the STRIVE phase of the research will be completed but the task will continue, as long as is needed, to ensure that Aboriginal communities no longer face the debilitating, stigmatising and ultimately health-compromising burden of curable STIs.

### Reference

1. The STRIVE team. **Investigators:** John Kaldor, James Ward, Alice Rumbold, Rebecca Guy, Basil Donovan, Christopher Fairley, Lisa Maher, John Boffa, Donna Ah Chee, Steven Skov, Matthew Law, Handan Wand, David Glance, Robyn McDermott. **Operational Group:** James Ward, John Kaldor, Alice Rumbold, Rebecca Guy, Linda Garton, Skye McGregor, Amalie Dyda, Debbie Taylor –Thompson, Bronwyn Silver, Belinda Hengel, Janet Knox (to May 2013). **Key stakeholder representatives on the STRIVE Executive (members current at September 1 2013):** Amanda Sibosado, Donna Ah Chee, Jacki Mein, John Boffa, John Loudon, Katy Crawford, Liz Moore, Nathan Ryder, Stephanie Trust.

### Acknowledgements

The National Health and Medical Research Council, management and staff at all participating health services, health departments in Northern Territory, Queensland and Western Australia, Aboriginal Medical Services Alliance Northern Territory, Apunipima Health Council (Queensland), Kimberley Aboriginal Medical Services Council, Westerns Diagnostic Pathology, Pathwest, Queensland State Laboratories.







Left: Neville Fazulla; and right: Neville and friends.

## Living positively: Neville's story

Howdy, my name is Neville Fazulla. Some of you will know me as Mona, Mony, Fuzzy or Olivia and my besties call me sis. I have been asked to give an insight into living with multiple chronic conditions and HIV and the ups and downs of what my journey has been like thus far.

I have five chronic conditions: I have lived with diabetes for 32 years, HIV for 21 years, kikuchi<sup>1</sup> for nine years, cancer for four years and end stage renal disease for three-and-a-half years. I believe that I manage all of these conditions effectively and have a number of strategies that I choose to practise that help me with my compliance and ongoing treatment. I have been lucky to live by, and have also been employed in, a self-management program developed by Dr Kate Lorig of Stanford University in California, USA. I will discuss this in more detail, but first, here is a bit of a background about me.

### Growing up

I am the fourth child of five in a mixed relationship marriage of both Aboriginal (Western Arrente and Yawarrawarrka) and Afghani descent. I am the first-born son, with three older sisters and a brother. We were raised in a very small little coal mining town in South Australia, which posed difficulties with isolation and seclusion. This was where our parents instilled us with strength and independence for our future lifestyles. In 1970 we moved to a more industrialised

town in South Australia (SA) and this is where I remember I first witnessed and experienced racism and discrimination.

Even though I knew I was different, it wasn't until the early 80s that I realised fully that I was gay – a 'homo' or a 'pansy', as the local rednecks would say. It was in the early 80s that I first heard of HIV, when it was still being called by the name GRID (gay-related immune deficiency), during a conversation with my mother after we had watched the local TV news. I wondered why my mother spoke to me about this disease and, later in life, I realised that she was giving me the opportunity to discuss and come clean about my sexuality in a way only a mother can.

### Moving out, coming out

Like many others, I chose to move away from my home town and state, so that I could live life as a gay man without any form of discrimination. I moved to Sydney in the late 80s, during the middle of the rise in HIV infection and transmission in the gay community. I met a beautiful man, fell in love and decided that I was comfortable with my life and lifestyle; I started to slowly 'come out of the closet.' Actually, I threw open the door and jumped out with all the glitz and glam – this was the first time in my life that I felt that I could be myself and not have to hide.

As a young man I was highly impressionable and believed that I was in the best ever part of the world a 'Whole

city full of men Gay Men,' so without sounding too cliché, this was the birth of a whole new person.

### Becoming positive, staying positive

When I first learned of my positive HIV diagnosis I was stunned and I continued to go about my everyday life in a state of numbness. At this time I was in a relationship with a very wonderful caring man and he provided me with terrific support.

I continued to work and questioned myself about how I was going to disclose to my family friends and work colleagues. I was more concerned at this point with 'coming out' to my boss. For months I dealt with the constant thoughts of death and what I wanted to do for the rest of my life. One conclusive decision was to continue to work, as I felt that this would enable me to be able to stay connected with society and give me an outlet.

This article is to share and discuss some of the self-management practices I've used over nearly 21 twenty years of living with HIV – practices that enable me to maintain and a somewhat stringent treatment and health regime.

I have never been one to allow my HIV to rule my life. Like everyone who has been affected by this disease, I have my good and bad periods, and fortunately, I have had more good than bad. I take a very positive and determined view of

the maintenance and treatment that I undertake for my HIV management. And oh yes, I did take ‘treatment holidays’ in the early 90s, as I found the maintenance at the time very difficult to cope with. I must state that this decision was not made lightly: I discussed my options of a treatment break with my treating doctor at the Albion Street Centre, Dr Derek Chan, and he was very forthcoming in listening to my reasons and providing me with different scenarios that could arise.

We compromised on a three-month treatment break, after which I would take up a new treatment regime: I have been compliant with this treatment since late 2004. I’m not saying that taking a break from treatments is the best decision for everyone, but if you are considering this you should discuss it with your treating doctor and have open and honest discussion about the pros and cons.

Compliance with medications and treatments is a somewhat a daunting experience. Currently, I take up to 31 tablets a day for a number of conditions, most are for my renal failure. I have found the models and enablers given in the Stanford program very effective and useful in addressing this issue.

I – like many of you – have suffered the grief that is accompanied with the loss of dear friends, mates and lovers, and I strongly believe that these losses are what strengthens my resolve to ensure that we continue to minimise the effects of HIV/AIDS on people’s lives and livelihood.



Arone Meeks' artwork (detail) created for World AIDS Day 2011.

## Overcoming addiction

I am active member of the gay, positive and Aboriginal communities – this has provided me with many great opportunities to grow and develop.

I have also had to deal with the demons associated with addiction. Like many a young gay man, I enjoyed the party and powder era and often found myself experimenting with recreational drugs. I found my greatest addiction was to heroin and ice throughout the early 2000s. As a number of you will remember, this was a very significant era in the gay party, clubbing and sex scene, and for many, these drugs were like a rite of passage to the ‘best party in the world’.

Throughout this period in my life, I believed that I was invincible and indestructible. Fortunately, I found out I was wrong and took measures to deal with stopping my addiction. I realised the cost financially and the impact health wise, and that I was losing a lot of friends because of my selfish behaviour due to the addictive power of the drugs. I sought help from friends and then chose to go ‘cold turkey’ I have been clean from these drugs for six years. I have also dealt with my marijuana, cigarette and alcohol reliance, and have ceased the use and consumption of these products.

## Work life

I have worked and socialised in the HIV/sexual health arena for a period of 21 years. I have been a project officer, team leader, president, coordinator, board member, student, mentor, a peer and volunteer and, along with all of this, a person working and living with HIV.

I have a very strong work ethic and believe that this is one of the enablers in my life that has helped me to stay relatively healthy and sane in dealing with my HIV. I continued to work until April last year, when I decided that I needed to cease work for a period of time while I dealt with the management and treatment of my renal disease, as I was finding it really hard to meet all my commitments in my work life and maintain a healthy model of treatment and lifestyle.

Some of the major barriers that I have faced are racism, discrimination and stigmatisation. I have dealt with the racism through two processes: cultural awareness

and competency, so in addressing these I use a set of processes. They are:

- open discussion and communication – the ability to understand the other person’s thoughts and reasoning (this is a two-way process)
- recognition of difference: the ability to recognise and accept difference
- education and empowerment to address difference using skills like acceptance, recognition and acknowledgement.

With discrimination and stigmatisation I believe that the best tool is to work towards finding out people’s fears and provide ways to dispel these fears. In most cases it’s just fear of the unknown. This is an ongoing process and requires patience and effective non-challenging communication practices.

## Living with chronic disease and practising self-management

Living with a chronic condition is a very challenging and difficult thing at times; there are people who do quite well and others who find it all too overwhelming. This could be for a number of reasons: anyone who deals with a chronic condition or illness understands and knows the feelings of anxiety, depression, grief and loss, fear of the unknown and ongoing peer and community stigma, and this can be especially compounded with HIV.

I am a strong advocate for self-management, as it gives me the knowledge and flexibility to maintain and strengthen my ability to have discussions – and I mean open and honest discussions! – with my health providers, be they doctors, nurses or allied health professionals. There are a number of ways to address issues around self-management – here I am going to discuss the Stanford Model.

The Stanford model of self-management (the Chronic Disease Self-Management Program<sup>2</sup>) is a very useful tool for dealing with chronic condition management. It is a peer-based course, delivered over a six-week period, which enables the individual to challenge their personal involvement in their ongoing health care. It provides a range of enablers and processes to address issues such as:

- understanding your health conditions and needs (i.e., understanding the differences between acute and chronic conditions)



- dealing with emotions
- working with and discussing your health care needs with your health providers
- developing future plans for health care
- relaxation methods
- communication practices
- food and nutrition
- depression and mental health needs
- medications and treatment decisions.

All of these techniques are used in a collaborative manner. They involve open discussion (this could be with a buddy or your health professional) and effective feedback and problem solving.

I find that using these models in my everyday life – for more than just my health concerns – has really made my daily living a lot easier and a lot less stressful.

The above are just some suggestions to be used. To get more information, contact your local health provider in your region to find out if these programs exist in your local area.

Enablers in all forms are the best way to deal with multiple diseases/disorders and a very effective tool and strong communication skills are key to dealing with arising issues and problems. There is a four step process that I routinely use:

- identify the issue
- express your feelings (use ‘I messages’)
- listen attentively (show respect for other people’s opinions/suggestions)
- clarify (ask questions if unsure).

### The challenge of multiple comorbidities

Dealing with one or two chronic conditions can be daunting, but having to deal with five was a whole new challenge. At first, my biggest issues were with medication compliance and time management. These two issues posed a new process of thought and decision making. This is at a time that I was lucky enough to be employed in Country Health South Australia, working with Aboriginal and remote communities to deliver the peer-based Chronic Conditions Self-Management Program. This provided me with a whole new set of skills to share with the community and adopt into my own health maintenance as well.

My life has dealt me some blows – and I mean some real strong ones – but I think

about what my beautiful mother used to always say: ‘If you’re knocked down, get up and keep going! You are the only person who can achieve what you want.’ Thanks Mum – I gather that this was about using positive thinking processes. I find I can achieve this by:

- writing down self-defeating thoughts
- processing them and changing them to rational and helpful thoughts about myself
- rehearsing the changes (i.e., stand in front of a mirror and give yourself positive reaffirmations)
- practising the changes (build them into your daily routine and health care communication and maintenance)
- being patient (like anything, it will take time to change your thought patterns and behaviour).

I suppose in a sense that is what has strengthened my resolve to continue to grow and not let any barriers stop me from achieving and having the life I want.

### Creating your own self-management toolbox

Listed above are some of the process and tools that I use and adapt to suit my own health maintenance and self-management. Each one of us is different and has individual needs and issues – do not lose sight of this and ensure that your own needs are met. For your own purposes, you could consider developing a personal Self-Management Toolbox of your own. This could be a written down on piece of paper on the wall, or a list of things on your mobile phone or tablet. Make sure the list is visible and you can refer to it at your convenience.

You can put a range of achievable processes into your toolbox such as medication issues, using your mind, planning, working with your health professionals, healthy eating, and fatigue and pain management. Put simply, a toolbox can be used for any decision making process in your life – don’t forget, they’re your tools!

If you are dealing with issues associated with access to treatments and ongoing care of your chronic condition maintenance please consider some of the processes I have shared, as well as making contact with your local health provider or community-based organisation.



Arone Meeks’ artwork (detail) created for World AIDS Day 2011.

In closing, don’t be afraid to ask questions. Do not presume that your doctor/health professional understands or knows what you are feeling or experiencing. Open discussion is the best medicine in this process.

Cheers,  
Neville Fazulla, Community Member

### References

- 1 Kikuchi is a form of cancer (named after the Japanese scientist who discovered the disease) that affects the Lymphatic system. It is a tropical disease that is very rare disease and is a tropical disease. There are less than ten known cases of Kikuchi in Australia.
2. <http://patienteducation.stanford.edu/programs/cdsmp.html>

Neville Fazulla is an Indigenous Australian with an extensive and varied career working with and representing Indigenous and gay communities. Over 21 years he has held staff or Board positions at organisations including Aboriginal Health and Medical Research Council of New South Wales, the Aboriginal Health Council of South Australia, the AIDS Council of South Australia, Queensland AIDS Council, People Living with HIV/AIDS South Australia, National Association of People Living with HIV Australia, Australian Federation of AIDS Organisations and many others. He has also been a community representative and spokesperson on numerous steering committees and community networks around the country.





Arone Meeks, *Celebration*. Handcoloured linocut, 2001. Edition of 30 (coloured state). Image size: 1190 x 1700 mm. Paper size: 1225 x 1800mm.

## The Anwernekenhe journey

By Michael Costello

The Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA) began its journey on 31 October, 1994 at Hamilton Downs just outside of Alice Springs. Beginning as a conference known as Anwernekenhe – First National Aboriginal and Torres Strait Islander Gay Men and Transgender Sexual Health Conference, Anwernekenhe bought together delegates to discuss the impact HIV/AIDS was having in the community and to find ways to address the affects of HIV as a major health care threat. The conference saw the establishment of a National Working Party, which over the years has had different names but is now known as the ANA.

At the completion of the Anwernekenhe conference, Arrernte Elders and

custodians of the land where the conference was held gave permission to use the word Anwernekenhe as the conference name. Anwernekenhe translates as ‘us mob meeting here in this place’. The conference set the foundations for an ongoing program which, at its core, was to be community driven, and so it continues to this day.

The working party formed at Anwernekenhe lobbied the Commonwealth Government, successfully gaining funding to establish a national project that would be auspiced by the Australian Federation of AIDS Organisations (AFAO). The national project operated from 1996 until 2010, coordinating a further three Anwernekenhe conferences held four years apart.

In 2008, the ANA became incorporated and decided to take on a broader brief: a whole of community approach. While we would still maintain a major focus on gay men and sistergirls, we recognised that the impact of HIV and AIDS was affecting the whole of our community. If we were to truly combat HIV in our communities, we needed community support. Positions on our Board were created for women and Elders to reflect this.

Incorporation and a broader brief did not come easy. It meant that the ANA was moving into a new direction and had to again prove itself as a stakeholder in the HIV response to Aboriginal and Torres Strait Islander communities.

At the end of 2010, funding dried up and we faced the real possibility of being



forced to wind up the organisation. The ANA Board in partnership with AFAO management initiated discussions with the AIDS Trust of Australia (ATA), successfully securing a grant which would be used to develop and implement the Anwernekenhe 5 conference – held in August 2011.

### A turning point

The Anwernekenhe conference and outcomes has proved to be a very successful model. The key elements of the process have seen four yearly national gatherings of Aboriginal and Torres Strait Islander people working in or affected by HIV. Conference participants form a consensus on agreed priorities and emerging issues, which then inform the work plan of the ANA. This provides a coherent, collaborative and consistent process for developing agreed strategic directions that result in a program that remains culturally specific and therefore more effective. While this process is effective, the ANA fully recognises that the needs of Aboriginal and Torres Strait Islander people affected by HIV are wide ranging, complex and in some cases unique. We also recognise that they are interconnected with many other health issues and that this model does not address the sexual health and HIV needs of all Aboriginal and Torres Strait Islander communities.

Anwernekenhe 5 proved to be a successful turning point for the ANA, with conference participants developing and agreeing to a strategic plan to take the organisation forward from 2011 until 2015. All participants at the conference had the opportunity to contribute to this plan, which was then refined by the ANA Board. Shortly after the release of the ANA strategic plan, the ATA agreed to a further grant which would see the ANA able to operate through until June 2013.

### A strong future

In April 2013, the ANA received the very exciting news that we would receive a three-year contract through the Commonwealth Department of Health and Ageing. With the contract commencing in the 2012/13 financial year and running until June 2015, this allows the ANA to consolidate implementation of our strategic plan. We are fully aware that there is still much more work to be done to grow into a viable organisation to



# anwernekenhe

NATIONAL ABORIGINAL AND TORRES STRAIT ISLANDER  
HIV/AIDS ALLIANCE



**Pictured from top:** the Anwernekenhe logo; participants at the Anwernekenhe 5 conference, August 2011, Cairns; and Marama Pala, Executive Director of INA (Māori, Indigenous & Pacific Island HIV/AIDS Foundation), at the Anwernekenhe 5 conference in Cairns.

meet the needs of Aboriginal and Torres Strait Islander people affected by HIV.

Over the next two years the ANA will focus its work on three priority areas:

- HIV partnership building, collaboration and community involvement
- HIV education, prevention, treatment, care and support
- organisational governance, strength and communication.

Some of this work will include preparations for Anwernekenhe 6 in 2015 – which will be the 21st anniversary of Anwernekenhe.

In the meantime, Australia will host the 20th International AIDS Conference (AIDS 2014), in Melbourne, in July 2014. The ANA is on the Australian Aboriginal Organising Committee (AAOC) for the Conference, ensuring community input into the Conference program, and oversight of the Sydney Indigenous Pre-conference.

The Sydney Indigenous Pre-conference is a collaborative partnership between the AAOC and the International Indigenous Working Group on HIV and AIDS (IIWGHA). The conference is expected to attract up to 300 national and international participants who will gather in Sydney in July 2014, prior to the International AIDS Conference. Further information on this conference will be made available on both the IIWGHA and ANA websites: [www.iiwgha.org](http://www.iiwgha.org) and [www.ana.org.au](http://www.ana.org.au)

Michael Costello is Executive Officer of Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA). He has over 18 years' experience working with the community response to HIV – both nationally and internationally – and has been involved with the ANA movement since 1998. Michael is Central Arrernte of the Arrernte Nation. He is a guest editor of this edition of *HIV Australia*.

## Our Destiny Haz Arrived: a national HIV prevention and testing campaign for Aboriginal and Torres Strait Islander gay men and sistergirls

By Michael Costello

Among Aboriginal and Torres Strait Islander people, gay men, sistergirls and transgender people remain at highest risk of acquiring HIV. There is an ongoing need to regularly provide these communities with culturally appropriate information on HIV and sexually transmissible infection (STI) prevention and treatment, care and support.

The Anwernekenhe National HIV Alliance (ANA) in partnership with the Australian Federation of AIDS Organisations (AFAO) is in the process of developing a multi-year campaign entitled *Your Destiny*, a national Aboriginal and Torres Strait Islander HIV prevention, testing and treatment campaign. This poster (pictured opposite) is the first resource associated with the larger campaign roll-out.

*Destiny Haz Arrived* is an Aboriginal community drag celebrity who is popular among community members, and who has appeared at a range of community sporting and social events in Queensland and Northern NSW over a number of years. *Destiny Haz Arrived* is a uniquely home grown Aboriginal superhero-type character, and utilises the superhero persona as part of her performances and outreach appearances. Superheroes are an archetype that has proved very successful in engaging Australian Indigenous communities in relation to sexual health information and behaviour change over the last 20 years.

The primary target audiences for the resource are:

- Aboriginal and Torres Strait Islander gay men and other men who have sex with men
- Aboriginal and Torres Strait Islander sistergirls and transgender people.

The secondary target audiences for this resource are:

- Aboriginal and Torres Strait Islander people aged 15 to 30
- Aboriginal and Torres Strait Islander people who inject drugs
- Aboriginal and Torres Strait Islander people with HIV

The aims and objectives of the campaign are:

- to enhance awareness of HIV and STIs among Aboriginal and Torres Strait Islander populations, in particular, among Aboriginal and Torres Strait Islander gay men and sistergirls
- to encourage regular use of condoms among Aboriginal and Torres Strait Islander populations, in particular, among Aboriginal and Torres Strait Islander gay men and sistergirls
- to highlight the importance and encourage the use of clean injecting equipment among Aboriginal and Torres Strait Islander people who inject drugs
- to promote regular HIV and sexual health testing among Aboriginal and Torres Strait Islander populations, especially among gay men and sistergirls.

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# OUR DESTINY HAZ ARRIVED

WE CAN  
**STOP HIV**

CONDOMS AND  
NEW SYRINGES  
KEEP **US** SAFE

HAVE **YOU**  
HAD YOUR  
SEXUAL HEALTH  
CHECK-UP?

**ASK FOR**  
AN HIV TEST



Australian Federation  
of AIDS Organisations



**anwernekenhe**  
NATIONAL ABORIGINAL AND TORRES STRAIT ISLANDER  
HIV ALLIANCE



# 2 SPIRITS

## Promoting Aboriginal and Torres Strait Islander gay men and sistergirl sexual health in Queensland: The 2 Spirits program

By Michael Scott

### Program history and summary

The 2 Spirits program was originally established to provide health education and community development to Aboriginal and Torres Strait Islander communities and to establish networks for Aboriginal and Torres Strait Islander gay men and sistergirls across Queensland. In addition, since its inception the 2 Spirits program has continued to provide direct one-on-one support advocacy and referral for Aboriginal and Torres Strait Islander people living with HIV.

The program was originally established in 1996 as the Queensland Aboriginal and Torres Strait Islander HIV/AIDS Project (QATSIHAP). In 2009 the name of the program was changed to '2 Spirits'. The term '2 Spirits' refers to a person whose body simultaneously houses masculine and feminine spirits. The rebranding of the program promoted the importance of culture in health education to Aboriginal and Torres Strait Islander communities.

The 2 Spirits logo was also launched in 2009. Developed by Arone Meeks, the logo features male and female images, along with the symbol of infinity. The colours of the logo reflect the colours of the rainbow, as well as colours featured in both the Aboriginal and Torres Strait Island flags.

Although a part of Queensland Association for Healthy Communities ('Healthy Communities'), the 2 Spirits program is funded primarily by OATSIH (Office for Aboriginal and Torres Strait Islander Health). This enabled the program to continue despite the defunding of Healthy Communities by the Queensland State Government in 2012.

Covering the entire state of Queensland, the program promotes the health of Aboriginal and Torres Strait Islander gay men and sistergirl communities through sexual health promotion, campaigns, community outreach, education workshops, support and referrals.

### The Whole of Community approach

2 Spirits utilises a 'whole of community approach' (providing education to the entire community) to provide health education about HIV and other sexually transmissible infections (STIs) and blood borne viruses (BBVs), and to reduce stigma and discrimination experienced by Aboriginal and Torres Strait Islander gay men and sistergirls. This approach has been highly effective, as it is culturally appropriate and allows the program to reach gay men and sistergirls in remote and regional community settings.

While our primary target groups are gay men and sistergirls, we always use a whole of community approach because it is extremely difficult to reach these groups using a more targeted approach – particularly in regional and remote communities. We cannot simply turn up to a community and ask to speak with 'gay men and sistergirls only', as this would immediately 'out' these people. Another advantage of using a whole of community approach is that it includes men who have sex with men – people who would not necessarily engage with education targeting gay men and sistergirls. The whole of community approach normalises sexual health discussion, making it accessible to everyone.

### Diversity of the program

2 Spirits is an extremely complex and multi-layered program, and faces challenges that many other programs do not have to overcome, including:

- **Geographical spread:** the program covers the entire state of Queensland, reaching from the southern borders of NSW to the Torres Strait, and from the eastern coastline to the Northern Territory (NT) border. The program has two offices (Brisbane and Cairns).





**Pictured clockwise from top left:** The 2 Spirits program visits the Northern Peninsula Area (NPA); dancers at the Laura Dance Festival; Workshop participants in Umagico, NPA; 2 spirits gathering of Elders in Brisbane; Arone and Nikki staffing the Condoman stall, NPA; and Yarrabah community education (just outside Cairns).



- **Cultural diversity:** Indigenous culture is not all the same across the state of Queensland. There are significant differences between Aboriginal culture and Torres Strait culture, and also between different communities across the state. What may work well with one community may be completely ineffective in another, hence our cultural strategy must be specific to each community we visit. Similarly, there are major differences between urban, regional and remote communities.
- **Competing priorities:** HIV and sexual health are just some of the many issues affecting Indigenous people across Queensland and Australia and are arguably not at the top of the list of everyone's priorities. Similarly, the needs of gay men and sisters are not at the top of the list of priorities for Indigenous people. The program works hard to promote the importance of sexual health; however, this is always within a context of relatively poor health outcomes for Indigenous people.
- **HIV sector workforce:** Within the HIV sector, Aboriginal and Torres Strait Islander needs are poorly understood. People within the sector promoting the importance of 'peer education' are often not peers of Indigenous community.

### Community visits and Elders Forums

The program has developed a series of Elders Forums, which involves the program speaking with Elders of the community who guide the program on the needs of the community. The program cannot only focus on Brisbane and Cairns; it must target a range of remote and regional communities to reach its target populations. When preparing to visit a community, the program takes a series of steps to ensure this has the greatest opportunity for success as possible. These steps involve:

- Identifying key health workers within a community, and working with them to determine what is best for the community
- Identifying and speaking with Elders of the community to guide the program on community needs

- Making an initial visit to introduce the program to the community
- Follow up with multiple visits to build rapport and trust with the community
- Delivery of an Elders Forum involving community Elders, and a community stakeholder gathering of health workers and community members
- Evaluation of community events to gather suggestions for the future.

It is important to be patient through each of these steps. Some communities will require several years of community visits before our education can be delivered. Nothing can be forced on a community – at times we have been completely prepared for a community visit only to discover the community is dealing with sorry business (bereavement), and we are forced to cancel our visit. Similarly, when working in regional Queensland, flooding may make some communities inaccessible at parts of the year and this is not always predictable.

Within our community visits, we often deliver 'Creating Inclusive Services' – a training package that targets service providers to make their workplace more inclusive to LGBT people (including Aboriginal and Torres Strait Islander clients).

### Northern Peninsula Area (NPA)/ Torres Strait outreach

The 2 Spirits program has visited the Northern Peninsula Region a number of times in recent years, each time building on previous successes and building trust within the communities visited.

In 2011, the program conducted a 'condom festival' in conjunction with Bamaga Sexual Health involving a series of workshops targeting HIV, viral hepatitis transmission and sexual health education through the whole of community approach. Community visits were conducted in the communities of: Injanoo, Umagico, New Mapoon, Siesia, and Thursday Island.

To assist with building trust within these communities, 2 Spirits worked with the Sexual Health Education Unit and Family Resource Centre in Bamaga, the

Bamaga Hospital as well as the Torres Strait Island Sexual Health Services.

Subsequent to these visits, 2 Spirits have been involved in Kasa Por Yarn in the Torres Strait. The Kasa Por Yarn (Just for a Story) Project was developed by Queensland Health and 2 Spirits as part of a multi-pronged strategy to develop and promote positive health messages for Aboriginal and Torres Strait Islander communities in some parts of Queensland. Kasa Por Yarn is a 12-part radio play now being broadcast throughout the Torres Strait.

The program was involved in the Kasa Por Yarn launch of Kasa Por Yarn 2, in Umagico, Northern Peninsula Area in 2012. Our involvement in this exciting project opened up avenues for further health promotion in this region which will involve upcoming visits to the Northern Peninsula Area to promote sexual health.

Further to Kasa Por Yarn, 2 Spirits has been involved in the 'Qualitative Research Living History Project'. This project, based in the Northern Peninsula Region, seeks to better understand the sexual health risks experienced by gay men and sisters through a series of in depth interviews of community members from the Northern Peninsula Region. The research will be invaluable in guiding future education in the region targeting gay men and sisters.

### Working in urban settings

2 Spirits work is extremely different within the urban centres of Brisbane and Cairns. Within Brisbane we collaborate closely with other organisations that work with our target group – specifically Open Doors (who work with young lesbian gay, bisexual and transgender [LGBT] people), ACPA (Aboriginal Centre for Performing Arts) and BIMA (Brisbane Indigenous Media Association). We also work closely with members of gar'bandjee'lum, a social group for LGBT Indigenous people from Brisbane and surrounding areas (see the story on page 24).

An example of health promotion within Brisbane is Brown Sugar, which is an Indigenous LGBT dance party with an annual theme. Organised by



gar'bandjee'lum and 2 Spirits, Brown Sugar attracts 150–300 people each year and allows the 2 Spirits program to tailor unique sexual health messages and conduct social research in an environment which is fun, safe and embracing of Indigenous and LGBT cultures.

Within Cairns we collaborate closely with other service providers; primarily, these are: CISHWN (Cairns Indigenous Sexual Health Workers Network), CHIVAS (Cairns HIV Services), RASHAC (Regional Area Sexual Health Advisory Committee) and Cairns Sexual Health. Additionally, we also work with Apunipima, Wu Chopperin, Positive Directions and Queensland Positive People, as well as Yupla Mipla Ahfla, a social group for LGBT Indigenous people in Cairns.

The program also provides one-to-one support for Indigenous people living with HIV. This is strongly utilised in Cairns, where there are a shortage of services available for the community generally. This service is not a case management service, and is more focused on bridging a cultural gap between Indigenous community and the service provider.

### Condoman and Lubelicious

The 2 Spirits program is probably best known for its development of the Condoman and subsequent Lubelicious and STI characters.

Condoman was originally developed in 1987 (Townsville) by Aunty Gracelyn Smallwood and a team of other Aboriginal Health Workers in response to the Grim Reaper campaign, which was being shown on TV at that time. As a character, Condoman became synonymous with his sex positive safe sex message, 'Don't be Shame Be Game'. In 2009, the 2 Spirits program relaunched Condoman with a new look and the first Condoman Comic Book.

In 2013, 2 Spirits relaunched Condoman with a female sidekick Lubelicious and a range of STI characters representing the STIs HIV, syphilis, gonorrhoea, chlamydia, HPV, hepatitis B, herpes as well as another character called 'Stigmalien' representing the stigma attached to STIs and sexual health.



**Pictured top:** The 2 Spirits program's Stradbroke Island Retreat participants, and **above:** Arone and Nikky, NPA.

A series of resources have been developed: the second comic, 'Condoman and Lubelicious'<sup>1</sup>, which introduces all characters, plus a range of character costumes to be worn by actors in community settings to bring the characters to life. Additionally, the 2 Spirits program has collaborated with BIMA (Brisbane Indigenous Media Association) to develop a series of radio skits to give the characters a voice, to promote sexual health on radio, and to de-stigmatise sexual health within Indigenous communities.

**For more information on the 2 Spirits program, you can view our Facebook page at: <https://www.facebook.com/#!/twospirits.qahc> or call us in Brisbane (07) 3017 1777 or Cairns (07) 4041 5451.**

Michael Scott is the Manager of the 2 Spirits program at Healthy Communities, in Brisbane, Queensland.

### Reference

- 1 For further information, and to access the Condoman and Lubelicious comics online, see: <http://www.qahc.org.au/condoman>





## Us mob: gar'ban'djee'lum network

By Dion Tatow



gar'ban'djee'lum ('us mob') is an independent social network for Aboriginal and Torres Strait Islander gay men, lesbians, bisexuals, transgender people, sistergirls and brotherboys (GLBTSB) in and around Brisbane. The network, which grew out of the 2 Spirits program at Queensland Association for Healthy Communities (Healthy Communities), carries out the following activities:

- supports Aboriginal and Torres Strait Islander GLBTSB people
- advocates for and supports Aboriginal and Torres Strait Islander GLBTSB social issues
- shares information to support healthy lifestyles
- celebrates Aboriginal and Torres Strait Islander culture and sexual identity
- hosts social events
- raises funds to assist members to attend relevant Aboriginal and Torres Strait Islander and/or GLBTSB events.

In November 2012, gar'ban'djee'lum hosted a Healthy Lifestyles Retreat which was attended by 40 members. The retreat aimed to build participants' confidence and support them to make

informed, positive decisions regarding sexuality, sexual identity, drugs and alcohol, sexual health and general physical health and wellbeing. The retreat was also an opportunity to increase participants' knowledge of and access to services within the lesbian, gay, bisexual and transgender and Aboriginal and Torres Strait Islander communities.

Members participated in a series of workshops delivered and designed by health professionals that focused on HIV prevention and education. Presenters at the workshops included Neville Fazulla, a long-term Aboriginal HIV-positive advocate, who shared his personal journey of managing his health and wellbeing. Brett Mooney and Phillip Sariago from the 2 Spirits program at Healthy Communities provided vital information about HIV and other STIs, and stressed the importance of taking responsibility for one's own health. Phil Bennett from Queensland Positive People (QPP) focused on the support services provided by QPP to people living with HIV in our community.

gar'ban'djee'lum also hosts an annual Brown Sugar Dance Party. These events

**Pictured clockwise from top:**

gar'ban'djee'lum network Red Party for World AIDS Day 2012, Brisbane; Condoman, Dion and Steven; and Stradbroke Island Retreat participants.

focus on entertainment, socialising, fun and laughter, but also provide opportunities to promote positive health messages, inclusiveness and diversity. Staff and volunteers from the 2 Spirits program (including gar'ban'djee'lum members) use the event to educate Aboriginal and Torres Strait Islander people – particularly gay men, lesbians, bisexuals, transgender people, sistergirls and brotherboys – about HIV, sexually transmissible infections and blood borne viruses.

**Connect with gar'ban'djee'lum on Facebook at: <https://www.facebook.com/garbandjeelum>**

Dion Tatow is Manager, Social and Emotional Well Being Workforce Support Unit at the Queensland Aboriginal and Islander Health Council.



# PATSIN: the Positive Aboriginal and Torres Strait Islander Network

By Ian Saunders

'We are here right across Australia. Let's support one another by yarning through our journey.'

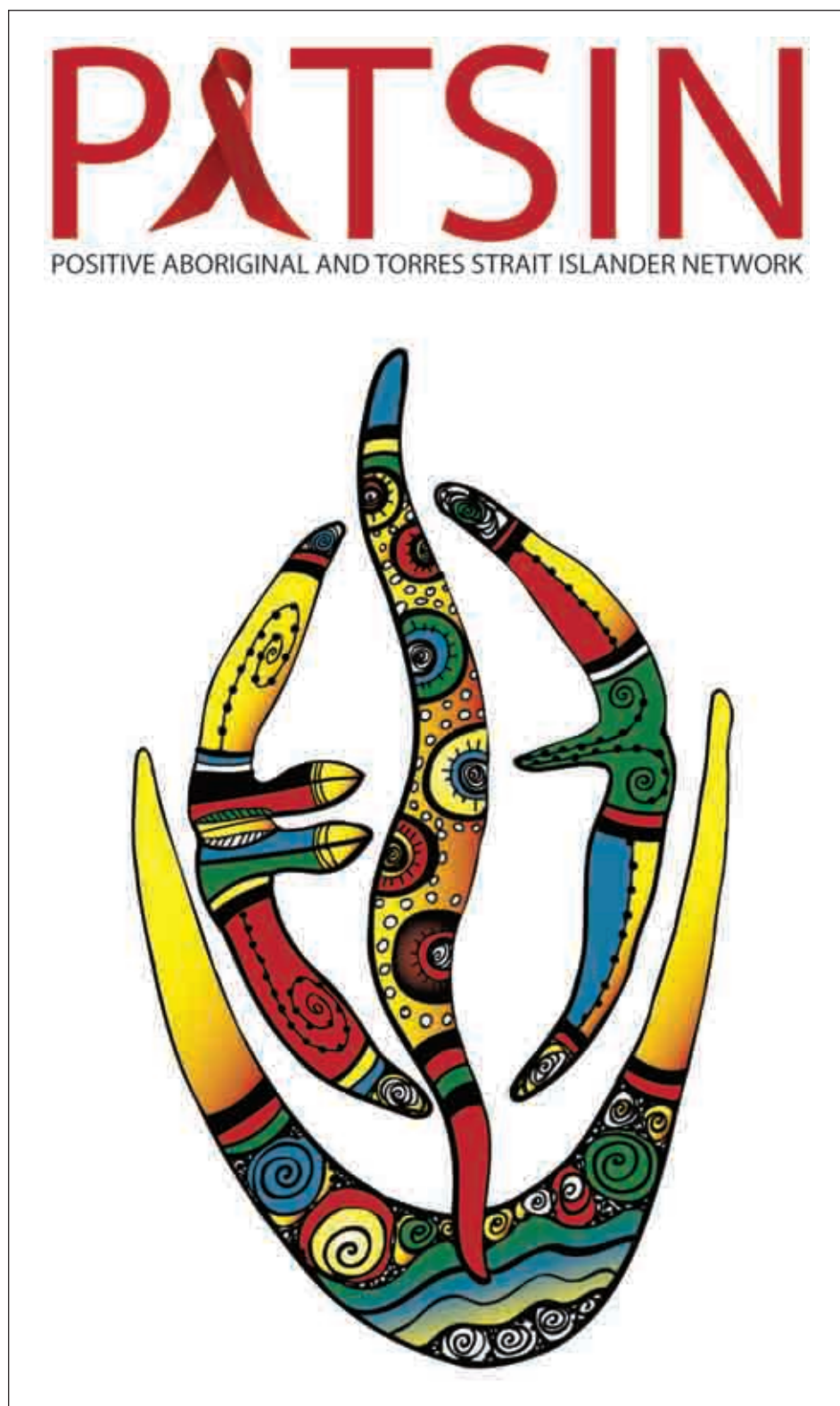
HIV peer-support systems have been successfully operating within Aboriginal and Torres Strait Islander communities since the beginning of the Australian epidemic. In June 2003, at a meeting in Adelaide, a group of positive brothers and sisters decided it was time to formalise this network.

That was when the Positive Aboriginal and Torres Strait Islander Network (PATSIN) began. In October of the same year, by a special resolution, PATSIN became an associate member of the National Association of People With HIV Australia (NAPWHA).

PATSIN is unique as it is made up entirely of Aboriginal and Torres Strait Islander people who are living with HIV. The group is currently at full capacity with ten active members. The group meets face-to-face and by teleconference throughout the year. Meetings are funded and organised by NAPWHA.

Our network seeks to do its work through a consensus-oriented process. This means that discussion and debate continues until everybody is satisfied with a result, not just the majority.

By incorporating our perspective into the work of NAPWHA, the network provides the opportunity for HIV-positive Aboriginal and Torres Strait Islander people to advocate for change at a national level. It also gives members the opportunity to network across their diverse communities; to identify best practice in health promotion; and to encourage the promotion of safe sex, safe needle use, HIV testing and early treatment. Perhaps most crucial of all, PATSIN provides culturally appropriate



The PATSIN logo, designed by Arone Meeks.

peer support to Aboriginal and Torres Strait Islander people with HIV.

We are committed to peer-based support and we have members in most of the states and territories of Australia. Contact us via our email: [patzin@napwha.org.au](mailto:patzin@napwha.org.au) or by phoning NAPWHA on Freecall™ 1800 259 666.

PATSIN is currently planning our involvement in the Global Village at

AIDS 2014. We are also represented on the Australian Aboriginal Organising Committee that is assisting the International Indigenous Working Group on HIV/AIDS to host the Indigenous Pre-conference in Sydney on 18 and 19 July 2014.

Ian Saunders is Convenor of the Positive Aboriginal and Torres Strait Islander Network (PATSIN).

# Ngalawi Djardi 'Sit & Yarn': ACON Health Retreat for Aboriginal and Torres Strait Islander People Living with HIV

Adapted from the 2012 Ngalawi Djardi Health Retreat Evaluation written by Meggan Grose

ACON has been working with Aboriginal and Torres Strait Islander People since its inception in 1985. In 1998 the ACON Aboriginal and Torres Strait Islander Project was established in acknowledgement of the Ottawa Charter emphasis on empowerment of at risk communities to self-determine ownership and control of the response to HIV and importantly, as a practical demonstration of commitment to reconciliation.

As part of this work, ACON has developed an annual health retreat for Aboriginal and Torres Strait Islander people living with HIV.

The aim of the Ngalawi Djardi Health Retreat is to increase the health and wellbeing of HIV-positive Aboriginal people and Torres Strait Islander people. Further, the retreat also works to help reduce the impact of HIV on Aboriginal and Torres Strait Islander people and their communities. Ngalawi Djardi achieves this through a combination of health promotion activities delivered within a culturally informed framework.

The name Ngalawi Djardi translates to 'sit and yarn'. This name captures the cultural context in which the retreat health promotion activity is developed. Ngalawi Djardi was coined by a community member in a competition run by the Aboriginal and Torres Strait Islander Project in 2011. The competition served as part of a broader community engagement and consultation process that aimed at listening to the experiences and perspectives of community members.

In the context of a continual evaluation and improvement process, the annual health retreat has undergone significant changes over the past 24 months. It is now delivered in collaboration with a range of partners, both with in ACON and externally. Indeed, the success of Ngalawi Djardi in recent years can be attributed to the cultivation of

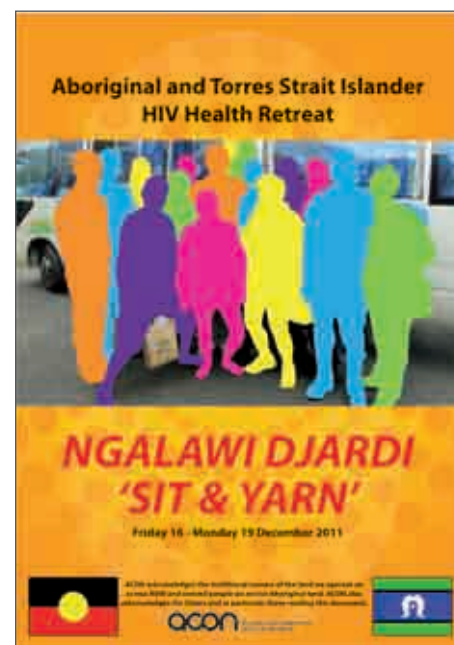
partnerships and collaborative work practices spearheaded by the then project coordinator, Meggan Grose. The partners in this project include the ACON HIV Health Promotion Team, the ACON Counselling Team and external partners including the Aboriginal Health and Medical Research Council of New South Wales, Positive Life NSW and experienced Aboriginal Facilitators.

Participants can opt into a range of health promotion activities including group information sessions, free time activities and social support through yarning to each other. The program is developed on experiential learning from the previous retreats the Aboriginal Project has conducted. The Body Mind Spirit Culture planning method is an example of a deliverable emerging from participant experience and now provides the program equal time dedicated to body, mind and spirit sessions – and the cultural framing for the entire retreat experience.

The model works on the basis that new features or concepts can be incorporated that might add value into the program via a cultural adaptation process which ensures alignment with the fundamental holistic and culturally relevant operating principle. It offers a much more innovative program model potentially than the standard process of only incorporating features that already meet culturally appropriate parameters.

The Ngalawi Djardi Sit and Yarn Health Retreats continue to evolve to meet the needs of Aboriginal people living with HIV every year. It is significant that in the 2012 retreat evaluation, 45% of the participants were not on treatment yet 75% reported that they knew how HIV treatments work to deliver both health and prevention benefits.

Body Mind Spirit Culture framing encourages renewal and innovation and further development of the model is



underway to ensure that the benefits gained from the retreat extend well beyond the weekend. We're also keen to see whether some features of ACON's Genesis program for newly diagnosed gay men – our most consistently 'outstanding' (by participant evaluation) peer workshop – might add value.

Finally, if there's a 'secret' to the success of Ngalawi Djardi, it's a pretty simple one; the participants determine the journey and the route it takes. Long may it be the case.

**The full Ngalawi Djardi Health Retreat Report is available at:**  
[www.acon.org.au](http://www.acon.org.au)





Arone Meeks, *Spirit Ark*, 2008, linocut, limited edition 35, 90cm x 150cm

## Celebrating strength: the role of resilience in responding to blood borne viruses and sexually transmitted infections among Indigenous communities

By Maurice Shipp<sup>1</sup>, Edward Wilkes<sup>1</sup>, John Kaldor<sup>2</sup> and Dennis Gray<sup>1</sup>.

<sup>1</sup>The National Drug Research Institute, Curtin University, Perth, Western Australia; and <sup>2</sup>The Kirby Institute, University of New South Wales, New South Wales, Australia.

‘Tangible strengths, such as young Indigenous people’s commitments to condoms and STI screening should be celebrated and bolstered to enhance their ability to protect themselves against adverse health outcomes and enhance their resilience against STIs.’<sup>1</sup>

### Introduction

The Indigenous resiliency project is a collaboration of International researchers examining the role that resiliency plays in responding to sexually transmissible infections (STIs) and blood borne viruses (BBVs) in Indigenous communities in Australia, New Zealand, and Canada.

The Australian arm of this research – which involves Indigenous researchers, peer researchers, and health service staff – is seeking to understand the role resilience plays in protecting Indigenous young people from acquiring BBVs and STIs. The project aims to identify and implement strategies to enhance these

protective factors, which can then be used by Aboriginal and Torres Strait Islander health services.<sup>2</sup>

The focus on resilience is of central importance to the project. This allows the research to step outside the discourse of disadvantage and to highlight health issues experienced by Indigenous young people in a way that is empowering and celebrates strength.<sup>3,4</sup>

### Background

In 2002, the Australian National Health and Medical Research Council (NHMRC), the Canadian Institute of Health Research (CIHR) and the Health



Research Council of New Zealand (NZ HRC) announced the establishment of a partnership to jointly invest in research which would contribute to improved health outcomes to reduce health inequalities for Indigenous people in each of the partner countries.

A grants scheme, under the name International Collaborative Indigenous Health Research Partnership (ICIHRP), was set up to support cross-country, multidisciplinary and multi-sectoral research and research translation, with the aim of building upon existing networks of Indigenous health researchers and to further develop research in a range of priority areas. The first call for funding submissions went out in 2004, and specified that applications should be made up of teams representing all three countries, and that submissions should address the theme of 'resilience' in Indigenous health.

In response to this call, an Australian research team was formed. It consisted of researchers from the National Centre in HIV Epidemiology and Clinical Research at the University of New South Wales (now known as the Kirby Institute) as well as leaders from three major Aboriginal community controlled health services, in Townsville, Sydney and Perth. The Australian team linked up with teams from New Zealand and Canada, and submitted an application that proposed a community-based research project, using qualitative and quantitative methods, to explore young Aboriginal and Torres Strait Islander people's resilience when facing the threat of blood borne viral and sexually transmitted infections.

The application was successful in the first ICIHRP funding round, and was the only submission in all three countries to be awarded funding that year.

A key component of the Australian project was working directly with the three participating Aboriginal Community Controlled Health Services (ACCCHS). ACCCHS are a unique feature of Australia's health landscape that distinguishes it from primary care services for Indigenous people in Canada, New Zealand and elsewhere. These services have direct access to young Aboriginal and Torres Strait Islander people, as well as clinical data with the potential to inform research and practice in this area. A key question for the research

team was whether the ACCCHS staff and management boards would allow access to this data for the purposes of the research.

### Phases of the research

The research plan developed by the Australian partners was made up of several phases. First, consultations would take place with each of the participating ACCCHS, including meetings with staff, management boards and external stakeholders. Second, a round of participatory action research would be implemented, through which ACCCHS could identify and address research questions of interest to them. Third, a clinical audit would take place, involving a review of services' experience with testing and other service provision for blood borne viral and sexually transmitted infection. Finally, a quantitative survey would be undertaken among young people attending, or in the catchment area of each service. All of the projects would require approval and involvement of the ACCCHS, as well as approval by relevant ethics committees.

Overall conduct of the project was to be guided by a steering committee made up of representatives of the university-based research team and all three ACCCHS.

Also within the steering committee an Indigenous Caucus was formed, which met separately and reported back to the steering committee. Study plans were approved by the steering committee, and then sent for approval to all relevant ethics committees.

The first phase of the research, conducted in 2006, included the setting up of processes and procedures to engage with focus groups and conduct in-depth interviews with service providers, young people, and other community members. The project then moved to the participatory action research (PAR) phase at two ACCCHS, in order to integrate research with practice and community involvement.

From the outset it was agreed that the development of interventions would be led from participating ACCCHS and their communities, with guidance and support to be provided through the research team. This work at one of the ACCCHS led to several reports and other publications<sup>5-7</sup> on the findings, and led directly into the survey phase of the research.

This phase involved development of questionnaires seeking information on experiences, understandings and behaviours relevant to understanding resiliency in relation to sexual behaviour, drug use and patterns of health service usage. Surveys were conducted among samples of young Aboriginal and Torres Strait Islander people – recruited from among clients of the participating ACCCHS, older high school students, and participants in community events – in Townsville, and Perth and south west WA, in 2010.

The surveys were conducted by staff from two ACCCHS with the assistance of staff from UNSW. The survey data were entered into a computer and analysed by staff from the ACCCHS and staff from UNSW and Curtin University. Analyses included a focus on knowledge, sexual and drug use behaviour, access to health services, history of sexually transmitted infections, and attitudes as measured by a previously published scale for assessing Indigenous resilience. Reports on this quantitative phase are being finalised at the time of writing this article.

### Professional ethics and cultural considerations

Despite a number of changes in membership of the team, a core of researchers and health service staff have followed the project through and completed most of the tasks we set ourselves. One of the three ACCCHS withdrew from the project during 2011. The team faced a number of issues that are by no means unique to this project, but were certainly highlighted by it.

A constant theme faced by the team was the need to ensure that there was proper respect and resourcing for Aboriginal community involvement. Intellectual property rights and ownership of the research must be sorted out before any research is conducted. The relationship between researchers is also a crucial factor; Aboriginal and non-Aboriginal researchers working together must understand the importance of professional ethics with regards to each other and be prepared to understand the cultural diversity within such a team.

Aboriginal ways of conducting research are not necessarily different; however, Aboriginal people have a historical



mistrust of research and researchers that must be recognised and taken into account. Aboriginal Australians may be more inclined to scrutinise and monitor the ethics and morals of research, and its possible links to various forms of oppression, dispossession and discrimination. The Aboriginal community, in many respects, is small and intimate thus researchers can ill afford to upset the balance as a result of their research. Miscommunications and misunderstandings, if not handled properly, can lead to anxieties and falling out among even the most well intentioned partnerships. Aboriginal Australians today are calling for research to focus on practical contemporary outcomes for families and community.

After the initial five years, the research team made the decision that leadership of the project should pass from the Kirby Institute to the National Drug Research Institute. The main reason for this change was the desire by the team for an Aboriginal researcher to oversee the project, and in a spirit of building Aboriginal capacity Associate Professor Ted Wilkes was asked to take on the role of Principal Investigator.

## Outcomes

The project is now in its final year, and can claim several real successes. First, it has collected new information about resilience of young Aboriginal and Torres Strait Islander people in responding to the risk of blood borne viral and sexually transmitted infections. So far, there has not been a major HIV epidemic among Indigenous communities in Australia, an outcome that must be understood if it is to be sustained. Both the qualitative research that has been published, and the quantitative data that are still being analysed, showed that young people have a good understanding of how to protect themselves from these infections, and adopt strategies that in many cases are likely to be effective. In preliminary analyses we have also found that those who have higher scores on the resilience scale are generally those who adopt these strategies, whether in regard to higher levels of safe sex practice, or greater avoidance of excessive alcohol or drug use.

Second, the research process has supported several ACCHS, and several

Aboriginal staff, to gain experience in the processes and purposes of research. Skills have been transferred in developing research projects, collecting data, analysing results and presenting to internal and external audiences. Techniques ranging from questionnaire design to data analyses are now much more familiar to some key Aboriginal staff at participating services.

Third, the university-based investigators have had many valuable insights and lessons into the way that Aboriginal health services and communities wish to engage with research processes and personnel. There are written guides for research conduct, but the best guide is always going to be experience.

On the other hand, the project met challenges along the way. It was immediately apparent that the funds provided by the project were barely enough to properly support research at one service, let alone three. After taking account of the coordinator salary and meeting costs, there was not enough to employ a full time person at each of the three ACCHS, and they found it difficult to recruit part-timers or split existing staff members roles. One consequence was that engagement in the project was never straightforward for participating ACCHS

The international element was difficult to operationalise on an ongoing basis. The team had annual meetings that were very fulfilling with international counterparts, and the occasional teleconference, but in reality the three countries operated quite independently. This was only to be expected, given the differences ranging from time zones to health systems to research priorities. The ICIHRP has very laudable aims, but practicalities may need more thought.

The conduct of research that is for the benefit of Aboriginal and Torres Strait Islander people is a key priority of the NHMRC, and it deserves to be commended for the ICIHRP funding initiative. We researchers, both Aboriginal and non-Aboriginal, are continually trying out new ways to achieve the twin goals of meeting the needs of communities, and meeting the demands of peer-reviewed competitive funding schemes. Through this project, we took many steps forward and probably a few



Arone Meeks' artwork (detail) created for World AIDS Day 2011.

back, but on the whole believe that we have advanced the cause of using research to improve the health of Aboriginal and Torres Strait Islander people.

This paper is written on behalf of the Indigenous Resiliency Project Partners including the Investigators and members of the Australian Steering Committee.

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**ntahc**  
northern territory aids & hepatitis council



# Live deadly stronger and longer: Ask for a Test

By the Northern Territory AIDS and Hepatitis Council

The Northern Territory AIDS and Hepatitis Council (NTAHC) has developed 'Ask for a Test', an Indigenous blood borne virus (BBV) and sexual health poster campaign.

To develop the campaign, Brett Trindle, NTAHC's Aboriginal Sexual Health Worker in Alice Springs, consulted with Aboriginal people and staff at the local Aboriginal Community Controlled Health Service (Congress). The consultation process revealed low levels of BBV and sexual health awareness and literacy within Alice Springs and surrounding Aboriginal communities. The consultation also provided ideas and information for the poster series concept and content.

The 'Ask for a Test' Aboriginal poster campaign was focus-tested with urban and remote Indigenous people in both Darwin and Alice Springs. Focus testing included a diverse cross-section of community members – from young Indigenous women to the Elders of communities, as well as Indigenous sexual health workers. This community input guided development of the campaign poster series. The posters have been produced for distribution to remote Aboriginal Community Controlled Health Services and remote clinics and other health services.

Central Australia Aboriginal Congress worked with NTAHC to develop and endorse the series. Feedback about the campaign included 'Awesome', 'LOVE them', 'the people are so real ... so everyday'.

Using images of a young Indigenous woman, two young men, a pensive older man and a strong proud man dressed in traditional ceremonial clothing has enabled the campaign to reach a diverse range of the Indigenous population with a strong message that ultimately says 'HIV is everybody's business'.

NTAHC is making the poster series available for rebranding so it can be used by other jurisdictions across the Territory and Australia. To date, Nhulunbuy, Yuendumu, Danila Dilba, Borroloola, Tiwi Islands, as well as Top End Remote Sexual Health and Blood Borne Virus Unit and the urban Darwin and Alice Springs teams, have all taken up offer to rebrand the campaign for use with their communities. Interstate interest has also been received from the Victorian Aboriginal Health Service, Hunter New England Local Health District in NSW. The process of rebranding posters for other jurisdictions is also underway.

Iterations of the poster campaign have been used for World AIDS Day, the Darwin Pride Festival and NAIDOC Week, as well as variations used on condom wrappers, web banners and email signatures.

The campaign is currently being evaluated. Contact NTAHC for more information.

**Further information about the 'Ask for a Test' campaign is available at <http://www.ntahc.org.au/news-a-events/indigenous-campaign>**



# The management of people with HIV who place others at risk (POAR): implications for Aboriginal people

By Natasha Pavlin

The *National Guidelines for the Management of People with HIV Who Place Others at Risk* (or 'POAR' for short) is a public health instrument that provides national guidance in relation to the management of people with HIV who are deemed to pose a public health risk of transmitting HIV to others. These guidelines, which operate slightly differently in each state and territory, allow for staged levels of 'coercive management' of individuals in relation to areas including HIV testing and counselling, supervision, treatment, detention, isolation and/or apprehension.<sup>1</sup>

In each State/Territory, an HIV Advisory Panel, overseen by a senior clinician, provides advice on the management of cases where support to the individual's primary health care provider is deemed necessary to achieve behaviour change.

## Disproportionate representation

While the number of people being managed by these mechanisms at any time is small<sup>2</sup>, we do know that Aboriginal people are over represented within these panels for assessment comprising somewhere between 20 and 30% of all panels cases. Are there implicit racist assumptions that make clinicians more worried about their HIV-positive Aboriginal patients and more concerned that they will place others at risk? What assumptions are these?

It is often assumed that Aboriginal people have particularly chaotic and mobile lives, that they have low levels of education and health literacy and low levels of self-efficacy. If all this is true – and then you add in mistrust in medical/health establishments, shame and fear, communication, language and cultural issues – then perhaps we can imagine why clinicians may have increased levels of concern and fear for Aboriginal patients with HIV. But is this fear justified and is this always the best approach? Are there any other supports that could be activated earlier to help people look after themselves as best they can?

## Levels of Intervention as outlined in the National Guidelines<sup>3</sup>

**The National Guidelines for the Management of people with HIV Who Place Others At Risk operate using five levels of intervention, with an underlying principle that '...for people with HIV who place others at risk, a variety of increasingly interventionist strategies may be needed, with preference being given to strategies that are least restrictive, as these will generally be the most sustainable and effective in the long-term.'**<sup>4</sup>

The five recommended levels of intervention are:

- **Level 1:** Counselling, education and support
- **Level 2:** Counselling, education and support under advice from HIV Advisory Panel or the Chief Health Officer or Equivalent
- **Level 3:** Management under Behavioural Order
- **Level 4:** Detention and/or Isolation
- **Level 5:** Referral of the individual to police.

Implementation of the Guidelines at jurisdictional level occurs with specific reference and attention to relevant jurisdictional legislation. Relevant provisions are primarily found within Public Health legislation and Crimes legislation.<sup>5</sup>

As we have moved to the treatment and management of HIV as a chronic illness and to the 'treatment as prevention' models, government-funded community supports – especially for those newly diagnosed and those not supported by not-for-profit groups – have dropped away.

The National Association of People with HIV Australia (NAPWHA) auspices a national network of Indigenous people living with HIV, PATSIN (Positive Aboriginal Torres Strait Islander Network). PATSIN comprises a committee of ten members who provide expert advice and advocacy issues related to the lived experiences of Aboriginal people living with HIV/AIDS.

## Epidemiology

The demographics of Aboriginal and Torres Strait Islander People diagnosed with HIV vary somewhat by jurisdiction; however, nationally – as is the case for the non-Indigenous Australian born population – Aboriginal and Torres Strait Islander people living with HIV are predominantly gay men and other men who have sex with men. What differs from the non-Indigenous Australian-born HIV-positive population is that injecting drug use is more likely and there

is a higher proportion of women and heterosexual people.

There has been much discussion and theorising as to why there has been no disastrous epidemic thus far within Aboriginal Australia, despite high rates of other sexually transmissible infections among this population. Some of these theories include: relatively closed sexual networks; not a high rate of partner change nor of 'risky' partners; good public health and harm minimisation in Australia in relation to people who inject drugs (thus far, anyway); and resource intensive but effective interventions in 'clusters' of infection to minimise further spread.

There is no reason, however, that an epidemic among this population might not occur in the future – and fears of this possibility may well be contributing to clinicians perhaps over-referring Aboriginal people to POAR panels.

Is there any particularly negative consequence of all this for Aboriginal and Torres Strait Islander people? Perhaps.

One of the most important truisms across all different communities of Aboriginal people is the importance of family, the importance of community and of



### Although Aboriginal and Torres Strait Islander populations have rates of HIV similar to the general population, Aboriginal and Torres Strait Islander people are named as a priority population in Australia's *Sixth National HIV Strategy*.<sup>6</sup>

This is for a number of reasons, including the potential for an acceleration of the HIV epidemic among Indigenous communities given:

- high prevalence of sexually transmissible infections (increasing the likelihood of HIV transmission) in many remote and very remote communities
- higher rates of injecting drug use and sharing of injecting and other equipment
- limited access to culturally appropriate services, including primary healthcare services in many communities
- the over-representation of Aboriginal and Torres Strait Islander men and women in prisons and juvenile detention
- the geographical, cultural and social circumstances of many communities, including high mobility, lower health literacy, and issues such as shame and underlying poor health status.

For Torres Strait Islanders, the movement and interaction of people between Australia and the Western Province of Papua New Guinea is a significant concern.

The National HIV Strategy is designed to work in tandem with the *Third National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2010–2013*. Priorities include a focus on injecting drug harm reduction interventions, detection and treatment of STIs, measures to reduce HIV-related stigma, and provision of accessible and culturally appropriate health services staffed by a skilled workforce.

#### Testing and diagnosis

Australian Bureau of Statistics data indicate there were just over half a million people identifying as Aboriginal and Torres Strait Islander living in Australia in 2006, representing 2.5% of the total population. More than a quarter of Aboriginal and Torres Strait Islander Australians reside in remote or very remote areas, compared with 2.3% of the non-Indigenous population.

Census data show a much younger profile for Aboriginal and Torres Strait Islander populations, with around 40% of people aged less than 15 years compared with 19% of the non-Indigenous population.<sup>7</sup>

Between 2002 and 2011, 219 Aboriginal and Torres Strait Islander people were diagnosed with HIV. Diagnoses were made in major cities, regional, remote and very remote areas. It is important to note that the total number of diagnoses among Aboriginal and Torres Strait Islander people is small so generalisations must be regarded with caution as changes may reflect localised occurrences rather than national patterns.

Rates of HIV diagnoses among Aboriginal and Torres Strait Islander populations have varied each year, although they declined slightly from around 4.5 per 100,000 (2002 to 2006) to around 4.3 per 100 000 (2007 to 2011). During those same periods, HIV prevalence in non-Indigenous, non-high HIV prevalence country of birth populations increased slightly from around 3.2 per 100,000 (2002) to 5.0 (2011).

Between 2007 and 2011, HIV transmission among people from Aboriginal and Torres Strait Islander communities was attributed to sexual contact between men in 59% of cases (including 8% of cases attributable to either sex between men or injecting drug use), to heterosexual contact in 17% of cases and injecting drug use for 16% of cases.

A far higher proportion of HIV diagnoses in Aboriginal and Torres Strait Islander communities were among women: 21% of new infections among Aboriginal and Torres Strait Islander cases compared to 8% among non-Indigenous, non-high prevalence country of exposure cases (2007–2011).

community and family responsibilities. One consequence of this is that very little is private in Aboriginal and Torres Strait Islander communities. The benefits of close knit communities can also backfire – HIV status can be used to victimise and exclude; therefore, we need to be particularly conscious of patients' privacy. Urban-living people may choose to be in the city partly for this potential for anonymity and mainstreaming – but this also means they may be cut off from other sources of support and therefore further marginalised. This can also be a reason why HIV-positive Aboriginal people may choose to seek their medical care in mainstream environments rather than from Aboriginal health organisations.

Being involved with a POAR panel can significantly impact on a person's capacity to maintain privacy about their diagnosis. Even if an individual is an appropriate client for POAR, how can we minimise

negative consequences for the individual? What other supports can we create and how can we raise awareness both within the mainstream and the Aboriginal and Torres Strait Islander communities to help HIV-positive Aboriginal and Torres Strait Islander people remain safe, well and connected to community? These are challenges which have, until now, gone largely unanswered but which need to be addressed.

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# HIV risk practices among Indigenous Australian and Anglo-Australian gay and bisexual men

By Toby Lea and Martin Holt<sup>1</sup>

## Background

Aboriginal and Torres Strait Islander ('Indigenous Australian') gay and other homosexually active men, transgender people and sistergirls are identified as priority populations in the *Third Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy*.

While there have been similar rates of HIV diagnosis per capita in the Indigenous and non-Indigenous populations over the past decade, there are differences in transmission patterns which could place Indigenous Australians at a higher risk of exposure to HIV. For example, in the five years up to 2011, around half of HIV notifications among Indigenous Australians were attributed to homosexual sex between men, compared to almost three-quarters of notifications among non-Indigenous Australians.<sup>2</sup> A much higher proportion of new HIV cases among Indigenous Australians was attributed to injecting drug use than among non-Indigenous Australians (16% vs 2%). An additional 8% of notifications among Indigenous Australians was attributed to men who have sex with men who also injected drugs, compared with 3% of notifications among non-Indigenous Australians.<sup>3</sup>

To date, there has only been one published study that has provided information about the sexual and drug use risk practices of Indigenous Australian gay and bisexual men. That paper, which analysed data from the Gay Community Periodic Surveys from 2000 to 2004, found that while there were no differences between Indigenous and non-Indigenous men in the proportion living with HIV (around 11%), Indigenous men were somewhat more likely to report unprotected anal intercourse with casual male partners (UAIC) in the past six months compared to non-Indigenous men (24% vs 21%), and almost twice as likely to report injecting drug use in the past six months (11% vs 6%).<sup>4</sup> We recently updated this analysis to

review HIV prevention, sexual health and harm reduction needs among Indigenous Australian gay men, using data from the Gay Community Periodic Surveys from 2007 to 2011.

## Methods

The Gay Community Periodic Surveys (GCPS) are anonymous, cross-sectional, self-completed surveys of gay and other homosexually-active men that are routinely conducted in six Australian states and territories. Trained staff recruit men at gay community events (e.g., Sydney Mardi Gras Fair Day), social venues (e.g., bars, clubs and gyms), sex-on-premises venues and clinics with high caseloads of gay men.

We included data from all Indigenous and Anglo-Australian men who participated in the survey between 2007 and 2011, representing 25,280 respondents, 1,278 (5.1%) of whom identified as Indigenous Australian. We compared Indigenous Australian and Anglo-Australian men on socio-demographic characteristics, HIV status, testing for HIV and STIs, sexual risk practices, and patterns of drug use.

## Results

### About the sample

Indigenous men were on average younger than Anglo-Australian men (mean age: 34 vs 37 years), were less likely to be full-time employed (62% vs 70%), and less likely to identify as gay (82% vs 89%). There were no differences between Indigenous and Anglo-Australian men in terms of HIV status (10% reported being HIV-positive, 76% HIV-negative). Among HIV-positive men, similar proportions of Indigenous men (77%) and Anglo-Australian men (74%) reported currently being on combination antiretroviral therapy. In the past 12 months, the majority of men had been tested for STIs (55%) and among men who were not HIV-positive, just over half had been tested for HIV (55%).

### Patterns of illicit drug use

The majority of men reported illicit drug use in the past six months (61%). While there was no difference in the proportion of Indigenous and Anglo-Australian men reporting any drug use, Indigenous men were somewhat more likely to use specific drugs, for example, cannabis (40% vs 34%), speed (24% vs, 16%) and heroin (4% vs 1%). Differences in the use of crystal methamphetamine (14% vs 11%) and amyl nitrite (38% vs 37%), were small. Erectile dysfunction medications were less commonly used by Indigenous men compared to Anglo-Australian men (14% vs 18%).

Indigenous men were twice as likely as Anglo-Australian men to report injecting drug use in the past six months (9% vs 4.5%). When taking into account the influence of socio-demographic characteristics (e.g., education and employment) and sexual and drug use practices, these differences became less pronounced. In the adjusted analysis, controlling for known differences between Indigenous and non-Indigenous men, Indigenous men were 43% more likely to report injecting drug use compared to Anglo-Australian men.

### Sexual risk practices with male partners

There was a small difference between Indigenous and Anglo-Australian men in the proportion reporting a regular male partner in the past six months (73% vs 69%), although both groups were similarly likely to report any UAI with regular partners (41% vs 38%). Among HIV-negative men with regular partners, Indigenous men were no more likely than Anglo-Australian men to report UAI with a serodiscordant partner (both around 5%). Among HIV-positive men who had regular partners, Indigenous men were no more likely than Anglo-Australian men to report UAI with a serodiscordant partner (40% vs 36%).

Two-thirds of men in both groups reported having had sex with casual male

partners in the past six months (66% vs 65%). However, while the proportion of men reporting casual partners did not differ according to cultural background, Indigenous men were more likely than Anglo-Australian men to report UAIC during this period (28% vs 21.5%). When adjusting for the effects of socio-demographic and behavioural characteristics, there was a slight attenuation in the difference reported, with Indigenous men remaining 30% more likely than Anglo-Australian men to report UAIC.

## Conclusion

In this paper, we found higher levels of recent UAIC and injecting drug use among Indigenous men compared to Anglo-Australian men, but no difference in self-reported HIV prevalence. These findings are consistent with the findings of the previous analysis by Lawrence and colleagues.<sup>5</sup> The higher occurrence of

UAIC among Indigenous men but similar HIV prevalence to Anglo-Australian men is noteworthy given that UAIC is a key route of HIV transmission.<sup>6</sup> This may suggest that the partners with whom HIV-negative and untested Indigenous men have UAIC come from sexual networks with a lower HIV prevalence (e.g., outside of major cities), or that Indigenous men are using risk reduction strategies such as serosorting and strategic positioning to reduce the likelihood of HIV transmission during UAI.<sup>7</sup> However, these interpretations are speculative and warrant further investigation.

The high rates of injecting drug use among both Indigenous and Anglo-Australian men were concerning, especially when compared with the low rates reported in the general population (around 0.5% of the general population reported injecting in the past 12 months in the 2010 National Drug Strategy Household Survey).<sup>8</sup> That Indigenous Australian men in our study were twice as likely as other gay and bisexual men to report injecting is mirrored in Australian HIV notification data, where Indigenous men diagnosed with HIV are twice as likely non-Indigenous men to be classified as homosexually active and a person who injects drugs.<sup>9</sup> This underlines the need for culturally appropriate harm reduction services for Indigenous Australian gay and bisexual men, whether men are accessing Indigenous, mainstream or gay-oriented services.

To our knowledge, this is the largest study of Indigenous Australian gay and bisexual men conducted to date, and these findings are likely to be valuable in focusing prevention priorities and support needs in this population. However, there are some important limitations. Firstly, the urban composition of the sample and gay community focus of recruitment means that caution should be taken in generalising these findings to men outside of urban areas and to those not engaged with the gay community. That said, the majority of Australian HIV diagnoses occur in major cities for both Indigenous and non-Indigenous men. Secondly, the Gay Community Periodic Surveys are brief surveys for the routine surveillance of sexual and drug use practices associated with HIV transmission. As such, detailed data are not collected that would provide a more nuanced understanding of HIV

risk practice, such as motivations for UAI, and barriers and incentives to accessing HIV and STI testing and treatment.

These findings suggest that Indigenous Australian gay and bisexual men should remain a focus for HIV prevention, care and support and the reduction of drug-related harm, but that they may not be at an elevated risk of HIV transmission for reasons that are not well understood. There is little or no research on the educational and support preferences of Indigenous Australian gay and bisexual men, or barriers to help-seeking. Our findings suggest this information would be valuable in guiding culturally appropriate HIV prevention and harm reduction services for this priority population.

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Arone Meeks' artwork (detail) created for World AIDS Day 2011.



# Findings from the Queensland Injecting Drug Survey (QuIDS): comparing hepatitis C risk behaviours among Indigenous and non-Indigenous people who inject drugs

By **Abhilash Dev<sup>1</sup>, Robert Kemp<sup>1</sup>, James Ward<sup>2</sup>, Suzanna Henderson<sup>3</sup>, Sidney Williams<sup>4</sup>, Andrew Smirnov<sup>3</sup>, Maria Plotnikova<sup>3</sup> and Jake M Najman<sup>3</sup>**

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An estimated 10,000 new hepatitis C (HCV) infections occur each year in Australia.<sup>1</sup> It has been estimated that 91% of new HCV infections are acquired through injecting drug use.<sup>2</sup>

A good deal of what is known about the transmission of hepatitis C and injecting drug use in Australia is based upon studies of the non-Indigenous population. Only a small number of studies have specifically recruited large samples of Aboriginal and Torres Strait Islander people who inject drugs (PWID) and few have concurrently recruited a comparison group of non-Indigenous PWID. There is a lack of data on risk-taking behaviours among Indigenous PWID but it is generally assumed that Indigenous Australians who use injecting drugs engage in a wide range of risk taking behaviours, and that those in custody are at the greatest risk of acquiring hepatitis C.<sup>3</sup>

The Aboriginal and Torres Strait Islander population may be disproportionately represented among people who inject drugs and are over represented among the Australian prison population. These two factors place Indigenous Australians at a higher risk of HCV transmission than others in the general population.<sup>4,5</sup> Current estimates suggest that the rate of HCV infections in the Aboriginal and Torres Strait Islander population is somewhere between two and ten times higher than in non-Indigenous populations.<sup>6</sup> While further research is required to test these estimates, studying the HCV risk behaviours among the Indigenous Australian population provides an indication of the HCV (and HIV) potential in this population group.

An analysis of participants in the Australian Needle and Syringe Program Survey, conducted since 1995, found

higher proportions of Indigenous than non-Indigenous participants were HCV antibody positive (57% vs 51%,  $p < 0.001$ ) and that Indigenous status and female gender were associated with HCV antibody seropositivity.<sup>7</sup>

The Queensland Injecting Drug Survey (QuIDS) was initiated in 2010 in response to concerns about increasing rates of injecting drug use and associated risk behaviours among Aboriginal and/or Torres Strait Islander people. Current users of injecting drugs, defined as having injected more than once in the previous 12 months, were recruited from 12 metropolitan and regional centres throughout Queensland. Participants were asked to complete a survey investigating patterns of drug use, risk factors, health status and health service access of current Indigenous and non-Indigenous PWID in Queensland.

QuIDS sought to examine systematic differences between Indigenous and non-Indigenous HCV-positive PWID. In our sample of injecting drug users we investigated the social determinants, patterns of use and overall health and wellbeing of those at risk of acquiring HCV infections comparing Indigenous and non-Indigenous PWID.

Findings of the study indicated that risk factors for HCV were similar in both groups; risk factors including injecting drug use, prior use of heroin and a current custodial sentence. Indigenous adolescents showed more markers of social disadvantage and higher rates of hepatitis B than non-Indigenous offenders.<sup>8</sup>

## Design and methods

QuIDS used respondent driven and peer network sampling methods to recruit 294 Indigenous and 275 non-Indigenous

injectors in ten urban and regional settings across Queensland. A number of peer interviewers were trained to recruit and interview study participants who were either known to them (convenience sample) or accessed through a systematic process of peer referral (respondent driven sampling). Participants provided informed consent and were reimbursed \$50 for their time in conducting the survey. The starting point for the respondent driven recruitment was through Queensland Needle and Syringe Program sites at specified locations.

## Findings

Table 1 (overleaf) sets out the QuIDS findings regarding demographic differences between Indigenous and non-Indigenous PWID. Indigenous PWIDs were slightly more likely to be female (38.8% vs 30.2%), be of younger mean age (31.0 vs 35.2 years of age), of lesser educational level (28.9% vs 37.4%), and to have had parents separated by the time they were 16 years of age (67.0% vs 51.3%). By contrast, non-Indigenous respondents were slightly more likely to identify as heterosexual (86.8% vs 82.8%), more likely to have slept rough (73.3% vs 63.6%) and to be living alone (30.5% vs 10.8%). On employment, income and imprisonment history Indigenous and non-Indigenous PWIDs were similar.

Table 2 (overleaf) suggests Indigenous PWIDs were more likely to have injected amphetamines (90.4% vs 83.5%) in the past six months, but the rates of injecting other drugs were similar. There were no differences between Indigenous and non-Indigenous respondents for reported first use of drugs, but Indigenous respondents were more likely to report that when they last injected they shared a needle (35.6% vs 18.9%). Non-Indigenous respondents

**Table 1** Comparing the social characteristics of Indigenous and non-Indigenous people who inject drugs.

Demographics	Indigenous	Non-Indigenous	P value
<b>Gender</b>			
Male	180 (61.2%)	192 (69.8%)	<0.05
Female	114 (38.8%)	83 (30.2%)	
<b>Age</b>			
Average	31.01	35.19	<0.0001
<b>Education</b>			
Lower secondary or lower	209 (71.1%)	172 (62.6%)	<0.05
Higher secondary or higher	85 (28.9%)	103 (37.4%)	
<b>Sexual Orientation</b>			
Gay/lesbian	20 (6.80%)	18 (6.6%)	NS
Straight	243 (82.6%)	236 (86.1%)	
Bisexual	30 (10.2%)	18 (6.6%)	
<b>Biological parents together till 16 years</b>			
Yes	68 (33.0%)	110 (48.7%)	<0.01
No	138 (67.0%)	116 (51.3%)	
<b>Slept rough</b>			
Yes	187 (63.6%)	200 (73.3%)	<0.05
No	107 (36.4%)	73 (26.7%)	
<b>Living alone</b>			
Yes	32 (10.8%)	84 (30.5%)	<0.001
No	263 (89.2%)	191 (69.5%)	
<b>Employment</b>			
Employed	71 (24.3%)	63 (23.0%)	NS
Unemployed	221 (75.7%)	211 (77.0%)	
<b>Income</b>			
Below \$400/week	196 (66.4%)	184 (66.9%)	NS
Above \$400/week	99 (33.6%)	91 (33.1%)	

NS = not statistically significant

**Table 2** Patterns of injecting drug use.

Drug use	Indigenous	Non-Indigenous	P value
<b>Injected in the last six months</b>			
Ecstasy	18 (29.5%)	12 (15.6)	<0.05
Amphetamines	253 (90.4%)	217 (83.5)	<0.05
Heroin	94 (58.4%)	110 (57.9)	NS
Prescription opiates	86 (65.6%)	116 (68.2)	NS
ORT drugs	55 (61.1%)	73 (61.3)	NS
<b>Type of user</b>			
Experimental	70 (24.0%)	52 (20.0%)	<0.0001
Recreational	162 (55.5%)	144 (52.5%)	NS
Work related	13 (4.5%)	23 (8.5%)	NS
Binge	100 (34.5%)	94 (34.6%)	NS
Dependent	119 (40.6%)	130 (47.8%)	NS
Non-dependent	93 (31.6%)	96 (35.2%)	NS
<b>Age first used</b>			
Average	18.7	19.2	NS
<b>Self-injected first time</b>			
Yes	69 (23.5%)	75 (27.3%)	NS
No	224 (76.5%)	200 (72.7%)	
<b>Shared in the last month</b>			
Yes	105 (35.6%)	52 (18.9%)	<0.001
No	190 (64.4%)	223 (81.1%)	
<b>Ever overdosed</b>			
Yes	83 (28.3%)	119 (44.4%)	<0.001
No	210 (71.7%)	149 (55.6%)	

NS = not statistically significant

were more likely to have ever overdosed (28.3% vs 44.4%).

Table 3 (opposite) examines the health history of Indigenous and non-Indigenous respondents in the sample. The results suggest that the two comparison groups have a remarkably similar health history, with similar levels of diagnosed self-reported mental illness (over 70% of both groups have been diagnosed with a mental illness), similar levels of diagnosed physical illness (almost 70% of both groups), and similar levels of trauma experienced in the past 12 months. Interestingly, Indigenous and non-Indigenous respondents had low (but similar) rates of self-reported HIV-positive status (3.0% vs 2.2%), and similar levels of self-reported hepatitis C-positive status (49.0% vs 55.9%).

Table 4 (opposite) compares the social characteristics of Indigenous and non-Indigenous respondents who were HCV-positive. The data suggests that there are few differences between Indigenous and non-Indigenous PWID who are HCV-positive. Where there were differences, these differences corresponded with differences in the whole sample; Indigenous HCV-positive respondents were younger, were less likely to have a higher level of education, were more likely to be living alone, and had a lower income.

## Discussion

Although HCV antibody status is based on self-report, there is evidence to support its use and overall validity.<sup>8</sup> In contrast to other studies of HCV among PWID in Australia, we did not find the Indigenous participants to be more likely to be HCV antibody positive – in fact self reported HCV infection was slightly lower among Indigenous participants (55.5% vs 61.8%). Instead, significant differences in reported HCV antibody positivity were most clearly reflected in key social determinant indicators such as having slept rough (61.8% vs 27.5%), being unemployed (58.7% vs 25.8%), and having been to prison (66.5% vs 38.5%). There were no significant associations between HCV infection and either mental or physical health. Having been diagnosed with a mental health condition or a physical health problem, or having a dual diagnosis, were similar for Indigenous and non-Indigenous respondents. With



regard to drug use, it is interesting to note that while the sharing of needles and syringes in the last month was more common among Indigenous respondents (35.6% vs 18.9%), this did not translate to greater levels of HCV infection – with a prevalence of 58.1% among Indigenous PWID who had shared in the past month compared to 67.5% prevalence among non-Indigenous PWID who had shared.

We suggest that HCV infection for both Indigenous and non-Indigenous PWIDs is grounded in a complex interface of social disadvantage, social capital and risk behaviours. This is a population existing very much at the margins of society with nearly half the population having been to prison, three out four people without employment and two thirds having an average weekly income of below \$400. Yet within this context the Indigenous participants demonstrate greater social capital. They were significantly less likely to have slept rough in the past (63.6% vs 73.3%  $p < 0.05$ ) and almost three times more likely to be living with others (10.8% vs 30.5%), suggesting Indigenous respondents were more likely to be in a relationship.

Strategies that simply focus on reducing risk behaviour without at least acknowledging the broader social context within which PWID live and interact will only have a limited effect – a more sustainable approach needs to account for and respond to the broader social determinants of health.

## Conclusion

This is one of the few studies of injecting drug use with a substantial sample of Indigenous respondents. This study demonstrates a remarkable homogeneity in responses from both Indigenous and non-Indigenous people who inject drugs. In contrast to other studies looking at social disadvantage, where findings indicate Indigenous status to be a significant predictor to greater social disadvantage, this study finds both the Indigenous and non-Indigenous respondents experience high and similar levels of social disadvantage.

Patterns of drug use were similar among both Indigenous and non-Indigenous PWIDs, with Indigenous respondents more likely to be injecting amphetamines in the recent six months. The relatively

**Table 3** Health history of Indigenous and non-Indigenous people who inject drugs.

Health issue	Indigenous	Non-Indigenous	P value
<b>Diagnosed mental illness</b>			
Yes	210 (71.2%)	213 (77.5%)	NS
No	85 (28.8%)	62 (22.5%)	
<b>Diagnosed physical illness</b>			
Yes	203 (68.8%)	189 (68.7%)	NS
No	92 (31.2%)	86 (31.3%)	
<b>Diagnosed mental and physical illness</b>			
Yes	172 (58.3%)	161 (58.5%)	NS
No	123 (41.7%)	114 (41.5%)	
<b>Experienced trauma in the last 12 months</b>			
Yes	246 (83.4%)	215 (78.2%)	NS
No	49 (16.6%)	60 (21.8%)	
<b>Blood borne virus infections</b>			
Self reported HIV-positive	7 (3.0%)	5 (2.2%)	NS
Self reported HCV-positive	120 (49.0%)	128 (55.9%)	NS

NS = not statistically significant

**Table 4** Associations between hepatitis C-positive status and social determinants.

Demographics	Indigenous (HCV-positive)	Non-Indigenous (HCV-positive)	P value
<b>Gender</b>			
Male	79 (53.0)	89 (56.0)	NS
Female	40 (42.1)	39 (55.7)	NS
<b>Age</b>			
Average	33.88	38.14	<0.001
<b>Education</b>			
Lower secondary or lower	94 (53.4)	83 (57.2)	NS
Higher secondary or higher	26 (37.7)	45 (53.6)	<0.05
<b>Biological parents together till 16 years</b>			
Yes	24 (44.4)	53 (59.6)	NS
No	61 (49.1)	57 (56.4)	NS
<b>Slept rough</b>			
Yes	100 (60.2)	110 (63.2)	NS
No	19 (24.4)	17 (32.1)	NS
<b>Living alone</b>			
Yes	23 (79.3)	43 (59.7)	<0.05
No	97 (44.9)	85 (54.1)	<0.05
<b>Employment</b>			
Employed	14 (27.5)	10 (23.8)	NS
Unemployed	105 (54.7)	117 (62.9)	NS
<b>Income</b>			
Below \$400/week	91 (53.2)	104 (64.2)	<0.05
Above \$400/week	29 (39.2)	24 (35.8)	NS

NS = not statistically significant

easier access to amphetamines might have contributed to amphetamines being nominated by both groups as the drug most injected in the last six months. Drug dependence was high in both groups, with recent heroin injection significantly associated with dependence. Non-Indigenous respondents were more likely to have experienced an overdose; this could be due to their increased use of opiates over their Indigenous counterparts.

Hepatitis C with its manifestations is an important public health issue because of its potential to increase health care costs. Of the three most common blood borne viruses among people who inject drugs (hepatitis B, hepatitis C and HIV), HCV is the most prevalent. The results from QuIDS suggest that Aboriginal or Torres Strait Islander status is relatively unimportant in the transmission of HCV. Consistent with other literature for similar populations, our results demonstrate

the significant association that age, homelessness, loneliness, unemployment, income and imprisonment have with a HCV-positive status.

#### Queensland injecting drug survey (QuIDS)

##### Project Team

**Project Advisory Group:** Coralie Ober, Jake Najman, Andrew Young (University of Queensland), Robert Kemp (University of Queensland), James Ward (Baker Institute IDI, Central Australia), Vanessa Gela (Queensland Injectors Health Network), Sidney Williams (Queensland Aboriginal Health Council)

**Chief Investigators:** Jake Najman, Sidney Williams, James Ward, Robert Kemp

**Associate Investigators:** Andrew Conroy, Abhi Dev, and Suzanna Henderson.

**Further information about the Queensland injecting drug survey is available at:** <http://www.uq.edu.au/qadrec/?page=157758&pid=20667>

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How are the Aboriginal Health and Medical Research Council's arts-based health campaigns engaging young Aboriginal people in NSW? Find out on page 46.



# Stigma and discrimination won't bring us down!

By the Scarlet Alliance Aboriginal and Torres Strait Islander Inclusion Working Party

Scarlet Alliance, Australian Sex Workers Association, is the national peak body representing the interests of sex workers in Australia. Through our objectives, policies and programs, we aim to achieve equality, social, legal, political, cultural and economic justice for past and present workers in the sex industry, in order for sex workers to be self-determining agents, building our own alliances and choosing where and how we work.

Scarlet Alliance works towards legal, health, industrial and civil rights for sex workers and uses health promotion focused approaches to achieve this. The tools Scarlet Alliance recognises as best practices include peer education, community development, community engagement and peer-led advocacy.

Sex worker organisations have a responsibility to actively work towards greater inclusion of the most heavily marginalised sex workers in order to legitimately and successfully represent the needs and diversity of our community. The voting membership of Scarlet Alliance has called for improved representation for Aboriginal and Torres Strait Islander sex workers in Scarlet Alliance and within the Australian sex worker rights movement.

## Sex work is real work!

We use the term 'sex worker' to refer to anyone who exchanges any form of sexual activity for money, favours, drugs, goods, accommodation, or any other form of reward. It is important to note that not all people who engage in transactional sex self-identify as sex workers, and this is the case in some Aboriginal and Torres Strait Islander communities where transactional sex occurs.

When we say 'sex work' we mean lots of activities, and it encompasses lots of people. We believe all sex work is work. We believe transactional sex is work. Transactional sex, for money or reward or survival, is a form of sex work. Regardless of how the person identifies, that work deserves human rights, industrial protections, occupational health and safety, and dignity. Not

identifying as a sex worker should not be a barrier to HIV prevention. How this plays out in educational settings is a challenge, however, and something that is of great interest to us as we endeavour to learn more about the specific needs of Aboriginal and Torres Strait Islander sex workers who do or don't identify that their sex for money or reward is sex work.

The Law And Sex Worker Health (LASH) study<sup>1</sup> (a joint initiative of the University of NSW and University of Melbourne, funded by the National Health and Medical Research Centre), compared three legislative models and found that sex workers working in NSW under decriminalisation had the best health and safety outcomes, and reported better relationships with police and health service providers than sex workers working under criminalisation or licensing systems. Decriminalisation is also recommended by the national HIV and STI strategies as the best practice model for allowing sex workers to achieve better sexual health.

Scarlet Alliance promotes decriminalisation of the sex industry as both a means to promoting the best health and safety outcomes for sex workers, and as a means to reducing the stigma and discrimination that sex workers can face in dealings with the legal system.

Governments, the public sector and the private sector all discriminate against sex workers. This discrimination results in a general acceptance of social stigma against sex workers and internalised stigma among the sex worker community.

The report *Unjust and Counter-Productive: The Failure of Governments to Protect Sex Workers from Discrimination*, published by Scarlet Alliance and AFAO, details that sex workers experience discrimination, in a variety of ways, on the basis of their occupation.<sup>2</sup>

With respect to the laws governing the sex industry the report found that:

*'... sex industry laws often actively discriminate against the development of,*

*and sex workers access to, mechanisms and legal remedies to address discrimination experienced in the workplace or in conducting sex industry businesses. This is particularly applied to sex workers who work in prohibited sectors of the sex industry.'*<sup>3</sup>

In 2013, sex workers are covered by some anti-discriminations protection in Queensland, Tasmania and the Australian Capital Territory (ACT). This includes Aboriginal and Torres Strait Islander people who work in the sex industry, even if that person doesn't identify as a sex worker. Anyone doing transactional sex or any other form of sex work, in Queensland, Tasmania or the ACT who experiences work-related discrimination can access legal protections; however, in the other states and territories these protections are not available.

Sex workers anywhere in Australia will tell you that individuals who are visibly read as Aboriginal or Torres Strait Islander will be specifically targeted by the police in criminalised settings. As such, the criminalisation of any kind of sex work in any location will inevitably have a greater effect on Aboriginal and Torres Strait Islander sex workers than others within the sex worker community.

## Aboriginal and Torres Strait Islander sex workers experience multiple discriminations

In the states and territories where licensing and criminalisation exists, Aboriginal and Torres Strait Islander sex workers, and also Pacific Islander and Māori sex workers, report being targeted by police for over-policing and harassment. While regular instances of racial profiling and abuses of police powers may not present anything new, it must be recognised that discriminatory laws surrounding sex work continue to result in the harassment of Aboriginal and Torres Strait Islander sex workers by both police and the general public.

And for Aboriginal and Torres Strait Islander sex workers it is not only police and laws that create barriers to health



Arone Meeks' artwork (detail) created for World AIDS Day 2011.

and human rights. Aboriginal and Torres Strait Islander sex workers who are survivors of sexual assault often face discrimination when accessing justice: firstly for being a sex worker, and secondly for being Indigenous.

The Australian Centre for the Study of Sexual Assault, in a briefing paper on 'issues of prevalence and disclosure'<sup>4</sup>, highlights experiences of victim blaming by police and the courts when reporting cases of assault and rape – as well as complainants being charged with offences, or arrested for previous ones, after disclosing assaults occurring in the context of sex work. These represent unique barriers to sex workers accessing justice.

Sex workers also experience discrimination and stigma inside some Aboriginal and Torres Strait Islander communities. Similarly, Aboriginal and Torres Strait Islander sex workers also experience discrimination within the sex industry; from bosses, fellow workers and clients.

Aboriginal and Torres Strait Islander sex workers are a particularly marginalised

group within the sex worker community, working at the intersection of whorephobia and racism and experiencing stigma and discrimination on a variety of levels. As such Scarlet Alliance believes it is important to understand these discriminations within the context of the sex worker community ... *even if the individual does not identify as a sex worker.* These discriminations stem from an array of intersecting issues relating to the sexual activity the person is engaging in. We believe all forms of discrimination against people engaging in sex work are unjust and a violation of our human rights.

Scarlet Alliance specialises in understanding and advocating for communities who experience discrimination as a result of their sex work. Some of the other communities that we represent who experience multiple discriminations include:

- street-based sex workers
- sex workers living with HIV
- migrant and culturally and linguistically diverse sex workers
- trans\* and sex and gender diverse sex workers
- sex workers who use drugs.

Scarlet Alliance is still at the learning stage in regard to Aboriginal and Torres Strait Islander sex workers. However, we are ambitious for the future; a future where Aboriginal and Torres Strait Islander sex workers are able to be represented, have access to services, and have strong support within their sex worker communities if they are discriminated against.

It is crucial, in order to increase the participation of Aboriginal and Torres Strait Islander sex workers in Scarlet Alliance activities, that we are able to make sex worker organising relevant to Aboriginal and Torres Strait Islander sex workers and effectively communicate the real benefits of that organising. The work that we do must be relevant to all sex workers, including sex workers working in long grass, isolated, and underground environments.

Scarlet Alliance believes that sex workers are sexual health experts and that our knowledge and resilience should be acknowledged. We promote peer education as a best practice approach to service delivery, where people with knowledge of, and experiences in, the sex

### What can our allies working in Indigenous health and the HIV sector do to support Aboriginal and Torres Strait Islander sex workers in our struggle for rights and recognition?

- Support sex worker organising
- Do not speak on behalf of sex workers. Hear and promote the voices of sex workers.
- Do not make assumptions about sex workers. Challenge stereotypes of sex workers when you encounter them.
- Support decriminalisation of sex work; it is the model promoted by organised sex workers and it benefits both sex workers and the wider community.
- Educate yourself on whorephobia and sex worker issues! Check out Scarlet Alliance's website, twitter, Facebook pages and more.
- Stay in touch with Scarlet Alliance. We have membership forms for sex workers, past and present. Even if you didn't identify as a sex worker when you were working, we welcome your membership now!

industry are employed as peer educators. Appropriate support for Aboriginal and Torres Strait Islander sex workers requires service delivery and representation that is both peer focused and culturally respectful. The primary way of ensuring this happens is for projects aimed at Aboriginal and Torres Strait Islander sex workers to be driven by Aboriginal and Torres Strait Islander sex workers.

**For further information, visit [www.scarletalliance.org.au](http://www.scarletalliance.org.au) or connect with Scarlet Alliance on Facebook at [www.facebook.com/groups/scarletalliance](https://www.facebook.com/groups/scarletalliance)**

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## ***Think About the Choices You Make:* creating a culturally appropriate sexual health promotion DVD for young Aboriginal people**

**By Laura Jenkins, Marnie Britton, Kate Green, Christine Edwards, Graham Smith, Karen Nairn and Karen Gillham**

### **Background**

Over the past decade, rates of sexually transmissible infections (STIs) have increased in Australia.<sup>1</sup> The most frequently reported STI in both Aboriginal and non-Aboriginal young people is chlamydia<sup>2</sup>, which often has no symptoms and can go undetected. Gonorrhoea is also a major concern for the Aboriginal population, with rates of diagnosis over 21 times higher than in the non-Aboriginal population<sup>3</sup>. Chlamydia and gonorrhoea are usually easily cured but if left untreated can lead to chronic pain, inflammation and infertility in both males and females.

The *NSW Sexually Transmissible Infections Strategy 2006–2009* lists both Aboriginal

people and young people as priority populations, on the basis of the prevalence of STIs in these groups.<sup>4</sup> NSW has been identified as having the largest Aboriginal population of any state or territory in Australia, comprising nearly 30% of the total Indigenous population.<sup>5</sup> In 2011–12, the internationally accredited Making Proud Choices sexual and reproductive health education package<sup>4</sup> was adapted by Hunter New England Population Health for use in a rural community in NSW with a high percentage of Aboriginal people. The Aboriginal sexual and reproductive health workers delivering the sessions identified the lack of a culturally specific audiovisual resource for Aboriginal young people as a gap in the youth education program. As a result, the

*Think About the Choices You Make* DVD was created by HNE Population Health.

### **About the DVD**

*Think About the Choices You Make* is a sexual and reproductive health education DVD appropriate for use by Aboriginal health workers, youth workers, teachers and other health professionals working with young Aboriginal people. The DVD has been approved for use by NSW Health.

Although the primary target audience is Aboriginal adolescents aged 16–19 years, the DVD is also intended to educate parents, carers, community, and service providers. The 12-minute DVD portrays how a group of Aboriginal teenagers

deal with the possible consequences of unprotected sex, including STIs and unplanned pregnancy.

Key messages in the DVD include:

- the importance of wearing condoms to protect against STIs and unplanned pregnancy
- where to access sexual health help and advice
- the availability of friends and family as a sexual health support network, and
- where to access condoms.

The film centres on two teenage couples, Tahlia and Jordan, and Ashley and Dean. The story is told in a documentary style, with the characters talking directly to camera about their experiences. These monologues are interspersed with flash-back scenes that show pivotal events in the story as the characters describe them.

## Development

The DVD was developed by the HNE sexual health promotion unit in collaboration with the HNE Aboriginal Sexual and Reproductive Health Advisory Group, and was produced by Red Hat Films. To ensure the finished product was culturally sensitive and relevant, Aboriginal community members and Aboriginal health workers from the Hunter New England area had input into the script at all stages of the script's development – first, second and final draft.

When considering the target group, the DVD was developed to be positive, fun, culturally appropriate, energetic and supportive. Special care was taken during script development not to be patronising, clinical or judgemental. Local Aboriginal youth (15–19 years old, male and female) were invited to take part in a confidential focus group with Red Hat Films' producer and scriptwriter. The young people gave feedback on the first draft of the script and the proposed cast. They also discussed young people's attitudes to a wide variety of topics including sex, STIs, music, fashion, friendship groups and culture, as well as their use of language.

During the casting process, actors and extras were selected from the local Aboriginal community wherever possible. An Aboriginal Community Liaison Officer assisted in recruiting local Aboriginal youth to work on the project.

## The story

**Ashley and Dean meet at a party one night and end up having unprotected sex. Ashley then visits the doctor with her best friends Tahlia and Lisa and asks for a prescription for the contraceptive pill. While she is there, the doctor also suggests she be tested for STIs and pregnancy because she did not use a condom during sex. Her pregnancy test results come back negative, but she tests positive for chlamydia. Ashley elects to tell Dean about it herself, which results in a heated argument between the two. Dean believes that chlamydia is a 'girl's disease' and that he couldn't have passed it on to Ashley. However, he eventually goes to the doctor for treatment and accepts responsibility as he has never used condoms during sex before.**

Tahlia and Jordan see the difficult time that Ashley and Dean go through after having unprotected sex, and do not want the same thing to happen to them. When they decide they are ready to have sex, they discuss it between themselves and also speak to trusted family members for advice. Tahlia visits the doctor with her mother, where she is given a prescription for the contraceptive pill, and Jordan talks to his father about using protection. As well as using the contraceptive pill, the couple ensure that they use condoms whenever they have sex.

Ashley and Tahlia also encourage their friend Lisa to take some free condoms from the clinic, just in case! Although Lisa is not in a relationship and not ready to have sex yet, she is happy that when she is ready to take that step, her friends will be there to support her like she did for them. The girls help and support each other through these difficult sexual health issues, without judgement of their differing views and experiences.

The boys also learn the importance of discussing sexual health together, realising that Jordan had previously been oblivious to the fact that Dean was taking risks and being unsafe. Ashley ultimately ends up talking to her mother about her experience, and learns that her mother is a good source of support for her. Ashley and Dean eventually make up, and ensure that they now practise safe sex all the time.

The music and artwork used in the DVD was developed by Aboriginal adolescents to promote sexual and reproductive health in their community as part of the Making Proud Choices program.

## Filming

While the DVD contains themes that all young people can relate to, the primary target group is young Aboriginal people. As each character introduces themselves to the camera, they identify the Aboriginal nation they belong to. To further enhance that cultural connection, Aboriginal-themed props were used liberally throughout the shoot; Aboriginal health promotion posters were displayed on the walls of the doctor's office where the girls attended for an appointment, an Aboriginal flag was shown in one of the character's bedrooms and the boys wore black, red and yellow Aboriginal wristbands.

In order for the documentary-style film to be as realistic and natural as possible, actors were encouraged to 'ad-lib' their dialogue, using words and phrases that they would use themselves in real life; the cast also wore their own clothes and applied their own make-up. To give the bedroom scene added authenticity, the actors assisted the production team in decorating the room with youth-friendly posters and props before filming commenced.

To ensure that the young cast members felt comfortable and safe, two Aboriginal health workers (one male, one female) were on set at all times to provide support and advice. The health workers also operated as cultural consultants during filming. The actors also had the opportunity to review each take they appeared in to ensure they were comfortable with the content.

## Educational supplement

The DVD is accompanied by an educational supplement for the worker to use after showing the film to a young audience. The supplement provides a summary of the key points raised in the DVD and possible questions to prompt thought and discussion around sexual health issues for young people.

The main discussion points covered by the education supplement include:

- the importance of condom use, options for contraception
- consequences of unsafe sex
- STIs not always having symptoms, and
- negotiating safer sex with a partner and sourcing sexual health support and information.

An evaluation survey is also included with the education supplement, and can be administered before the DVD is shown to ascertain the audience's basic



sexual health knowledge. The survey can be re-administered again after the DVD viewing and subsequent discussion, to ascertain whether the audience's basic knowledge has increased as a result of exposure to the resource.

### Access

The DVD can be viewed free of charge through the HNEHealth YouTube channel (<http://www.youtube.com/user/HNEHealth>). To purchase a hard copy of the DVD and educational supplement please contact the Hunter New England sexual health promotion unit on (02) 4924 6499.

### Acknowledgements

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Laura Jenkins (Project Officer at Hunter New England Population Health), Marnie Britton (Project Officer at Hunter New England Population Health), Kate Green (Aboriginal Sexual and Reproductive Health Worker at Hunter New England Population Health), Christine Edwards (HARP Health Promotion Manager at Hunter New England Population Health), Graham Smith (Aboriginal Sexual Health Worker at Hunter New England Population Health), Karen Nairn (HARP Director, Hunter New England Population Health), Karen Gillham (Director Health Promotion, Hunter New England Population Health).

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Stills from the *Think About the Choices You Make* DVD.



Children take part in the award-winning **Where's the Shame, Love Your Liver** campaign at Tharawal Aboriginal Medical Service



## Connecting with youth: how arts-based health campaigns are engaging young Aboriginal people in NSW

By Matthew Rodgers

The Aboriginal Health and Medical Research Council (AH&MRC) would like to acknowledge the input of Aboriginal communities and workers into these campaigns.

Conducting a successful health promotion campaign is demanding at the best of times – and rolling out a campaign about sensitive topics like sexual health and drug use to young Aboriginal people presents additional challenges. Aboriginal-specific resources relating to these topics are not easy to come by and mainstream messaging and standard health promotion material, like posters and mass media campaigns, often do not engage the interest of young Aboriginal people.

These were just some the challenges facing the Aboriginal Health and Medical Research Council of NSW (AH&MRC) when it was recently tasked with creating educational campaigns for young Aboriginal people to make informed choices about sexual and reproductive health, blood borne viruses (BBVs), and alcohol and other drugs issues.

As the peak representative body and voice of Aboriginal communities on health

in NSW, the AH&MRC's involvement was critical to achieving these goals at a state level. In planning an effective strategy for reaching young Aboriginal people with messages on sensitive topics, the AH&MRC facilitated focus groups with young Aboriginal people through its membership, which consists of around 50 Aboriginal Community Controlled Health Services (ACCHS) and Aboriginal Community Controlled Health Related Services (ACCHRS) located throughout the state.

Since the establishment of the Aboriginal Medical Service, Redfern in 1971, ACCHSs have led the way in terms of providing effective comprehensive primary health care for Aboriginal communities. Aboriginal community control has its origins in Aboriginal people's right to self-determination, as reinforced in the 2007 *United Nations Declaration on the Rights of Indigenous*

*Peoples*.<sup>1</sup> This is the right to be involved in health service delivery and decision making according to protocols or procedures determined by Aboriginal communities based on the Aboriginal definition of health, as stated in the 1989 *National Aboriginal Health Strategy*:

*Aboriginal health means not just the physical wellbeing of an individual but the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community.*<sup>2</sup>

Like its members, the AH&MRC is an Aboriginal community controlled health organisation, with a Board of Aboriginal community representatives selected regionally by AH&MRC members. The organisation's focus is to support, represent and advocate for the interests of ACCHSs in all aspects and



at all levels of the health care system, and to promote the unique and invaluable role these organisations play in health service delivery and policy development. AH&MRC is experienced in delivering quality health promotion campaigns, particularly around sexual health. For these reasons, the AH&MRC was successful in its proposal to deliver these campaigns at a much larger scale.

Since 2010, the AH&MRC has developed and delivered the following campaigns:

- **Where's the Shame, Love Your Liver**  
– aimed to increase awareness of hepatitis C in an environment where shame and stigma are prevalent (2011)
- **Staying Strong: Act Connect Survive**  
– aimed to build young Aboriginal people's resilience around drug use and BBVs (2013)
- **It's Your Choice Have a Voice: Rights, Respect, Responsibility**  
– aimed to increase young Aboriginal people's literacy around sexual and reproductive health and related AOD issues (2010 and 2013).

Although HIV was not specifically identified as part of these campaigns, HIV prevention was included in the sexually transmissible infection and BBV prevention messages in all the campaigns.

The local ACCHSs in each area played a key role in the delivery of the campaigns, and were relied on to organise local working groups, identify young people to be involved, help facilitate the educational settings, and organise the community events around the campaigns.

While the make-up of the local working groups varied, the group usually comprised of representatives from the local ACCHS, the Local Health District Sexual Health team, the youth development officer from the local council, Aboriginal Education Officers from local schools and other local workers. The AH&MRC provided a preparation workshop for the working group, and workers were also provided a support pack with resources and a detailed planning checklist, a letter to school principals, posters and flyers.

## First Steps

In 2010, funding was provided by the AIDS and Infectious Diseases Branch of NSW Health (now NSW Ministry

of Health) to undertake two arts-based community education campaigns to:

1. address sexual and reproductive health and related alcohol and other drug issues among Aboriginal adolescents, and
2. to raise awareness of hepatitis C prevention, treatment and management in an environment where shame and stigma are prevalent. Funding for the campaigns came from the National Partnership Agreements – Indigenous Early Childhood Development and the Indigenous Health streams. The program was expanded in early 2011 through funding from the Mental Health and Drug and Alcohol Office of NSW Health in order include key messages around drug and alcohol misuse.

Two different approaches for campaigns were developed:

- **It's Your Choice, Have a Voice**  
– occurred over three days, included workshops on campaign themes, dance workshops, hip hop song writing, resources with message themes for participants, and a Deadly Styles dance off at a local school.
- **Where's the Shame, Love Your Liver**  
– occurred over three days, included education sessions and activities around hepatitis C prevention, management and treatment, poster development, song writing workshops and video clip production, development of resources with message themes for participants, and a community event showcasing the video clips.

**Where's the Shame** later led to the **Staying Strong: Act Connect Survive** campaign using the same format.

All campaigns included a social media component (Facebook, YouTube, SoundCloud and website), managed and promoted by the AH&MRC.

The key messages of campaigns aimed to be positive in tone and resonate with youth and Aboriginal culture – with an action for participants to take away. The campaign messages were focus tested with young Aboriginal people to ensure their relevance.

The **It's Your Choice** campaign messages were that, in relation to sexual and reproductive health and drug and alcohol use:

- The choices you are making now can affect your future (choices and consequences)
- There is support available (identify a range of sources for support)
- Respect yourself, your culture, your family and partner to have healthy relationships
- You can be whatever you want to be; you have the power to make the choices that are right for you.

The **Where's the Shame, Love Your Liver** campaign key messages were:

- Hepatitis C affects everyone, families and communities
- Shame surrounds hep C but we need to talk about it
- Find out more about hep C from local health services
- Hepatitis C is in prisons, be careful inside; protect yourself and your families.

The involvement of recognised artists helped greatly to capture the attention of young people, many of whom were eager to take part in activities that featured dancers or artists they identified with or viewed as celebrities – such as the Deadly Award-winning hip hop group The Last Kinection, who were partners in rolling out the **Where's the Shame, Love Your Liver** and the **Staying Strong: Act Connect Survive** campaigns.

## Evaluation and reach

The two initial campaigns were evaluated in 2011/12 by an independent consultant, and included pre- and post-campaign focus groups, process evaluation collected at workshops, monitoring of Facebook data and reach, survey of local workers (via SurveyMonkey) and stakeholder interviews.

Key findings included:

- Both campaigns met their objectives and recall of messaging from focus groups was good.
- The medium of hip hop dance and song/film production was key for engaging young Aboriginal people.
- Using an arts-based campaign made it easier for local workers to discuss sensitive topics.
- The social media component assisted with the reach to other young Aboriginal people and their peers.

**It's Your Choice** was delivered to 14 communities in 2010, largely in schools.



**Pictured left:** Campaign volunteers helping to spread the message; and **right:** a selection of each campaign's promotional and support material.

Young Aboriginal people said they liked the way that the campaign was aimed at the whole school, so that the messaging around sexual and reproductive health and alcohol and other drug use wasn't identified as an 'Aboriginal' issue. A total of 4,000–5,000 young people are estimated to have been involved in the workshops and school Deadly Styles events.

**Where's the Shame, Love Your Liver** was delivered to ten communities, community events were largely held at local ACCHSs, and 13 posters, 36 songs and 31 film clips were developed by participants and distributed across NSW.

Facebook played an important role by building excitement and continuing the dialogue around the campaigns. The site statistics for **It's Your Choice** in 2011, for example, show that activity through the site increased dramatically as the campaign rolled on: between the second and third weeks of the campaign, traffic through the site increased by 50% to 1,000 visits in a week. Monthly users of the site peaked at over 1,700 by the end of the campaign.

There was strong agreement by virtually all stakeholders that a creative arts approach – and the use of hip hop music and dance in particular – was an appropriate and effective strategy for engaging young Aboriginal people and delivering positive health and wellbeing messages. However, it was not just the messaging that was important in the delivery of the campaign. The fact that the event was fun, something out of the ordinary for young people living

in towns where there are few such opportunities, and targeted teenagers' interests was critical.

Responses to post-campaign interviews and comments made on Facebook by workshop participants, organisers and other stakeholders indicate the campaign's success, and it's effectiveness in engaging young Aboriginal people, in particular:

*'I think it worked because it communicated with the kids on their level. They get so much health education at school, I think they start to switch off. This was fun and interactive.'* (Health Worker)

*'You have made me wanna do something i never wanted to do but today i applied for a scholarship to Griffith University to study the Bachelor of Music, thank you for making me realise that i can do something with my life.'* (Participant).

*'Its Your Choice Have a voice xx loved performing today glad i participated ive gained confidence and happiness and an even stronger feel for dance thanks heaps love you all xx loved salsa to realise how good I was you bring out the best in all of us thanks again xx.'* (Participant)

*'i just wanted to thank you for teaching me not only to dance but to have confidence to show what i can do and i really like to thank the dancers as well for teaching me that putting a salsa in my dance will build my [confidence] so thank you for everything and we hope you will come back to Balranald :D'. (Participant)*

*'I learnt to respect myself an others an to have a go an dnt be afraid to do wat i want an if yous didnt come to balranald*

*then i dnt think id be able to dance infront of any1 or even get up infront of any1 so thankz an I really hope u come back to balranald'. (Participant)*

*'You guys are just amazing ! You taught us "That Shames Out The Door" Get Out The Because Were Only Young & Were The Future Of Our Community ! Come Back To Coonamble High, Really Soon; You will see a change in all of the students :) you's guys made the 3 days of hip hop the best!'. (Participant).*

Matthew Rodgers is Media and Communications Coordinator at the Aboriginal Health and Medical Research Council of NSW. The Aboriginal Health and Medical Research Council would like to acknowledge the Traditional Custodians of the Land on which we operate and pay our respects to Aboriginal Elders past and present. We also gratefully acknowledge all of the Aboriginal community members and workers whose participation and feedback about the program has helped to shape and inform this article, including those quoted in the program evaluations reproduced above.

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# Mind The Gap: addressing HIV and STIs among young people in rural and regional areas

By Ann-Marie Roberts

In 2009, the Department of Education and Early Childhood Development released a report on the health and wellbeing of young people in Victoria which revealed over half of all sexually transmissible infection (STI) notifications (chlamydia, gonorrhoea, syphilis and HIV) were among young people aged between 15 and 24 years.

Chlamydia notifications had increased considerably between 2007 and 2008 in four of the five rural and regional Victorian areas, including Gippsland, Hume, Loddon Mallee and the Grampians. Syphilis and gonorrhoea notifications had also increased in the Loddon Mallee and Gippsland areas over the same period.<sup>1</sup>

A more recent 2011 report shows the trend continues, with STIs higher for young people in rural Victoria than metropolitan Victoria – this difference has become more pronounced over time. The highest and fastest growing rates of STIs among young people are for chlamydia.<sup>2</sup>

While chlamydia is the STI most commonly associated with adolescence, other STIs are also more common in younger rather than older individuals. Gonorrhoea is most common amongst men, especially those having sex with other men, but this disease still causes the greatest burden of disease in those under the age of 25 years.<sup>3</sup>

## Mind The Gap – a three-phase project

In response to the rising prevalence of STIs among young people in rural and regional areas, the Victorian Department of Health funded Family Planning Victoria (FPV) from 2010–2012 to implement Mind The Gap, a community engagement project.

FPV delivered the project in collaboration with primary partners – the Victorian Aboriginal Community Controlled Health Organisation and the Centre for Adolescent Health. Supporting partners were FAR Social Enterprises (NSW), The Twenty 10 Association (NSW) and the Burnet Institute.

The project targeted young people under the age of 29, with a particular focus on two priority groups: gay, lesbian, bisexual and transgender (GLBTIQ) young people; and Aboriginal and Torres Strait Islander young people.

Project aims included the primary prevention of HIV, STIs and blood borne viruses (BBVs) in young people. Fundamental to the project was working with key organisations and agencies to develop and implement social and health strategies to reduce STI and HIV transmission and raise awareness about sexual health, discrimination and diversity in GLBTIQ communities and beyond.

The disparity in the burden of disease carried by GLBTIQ young people compared to heterosexual youth appears to be largely due to the impact of stigma and discrimination, combined with many young people's reluctance to access health care and screening due to perceived poor practitioner knowledge and sensitivity.

Despite some increases in legal protections for GLBTIQ citizens over recent years, social or cultural acceptance of GLBTIQ communities is still not a given, particularly in rural and regional areas. GLBTIQ people are more likely to face isolation, social exclusion and disconnection from family and community networks – factors which all contribute to increased risk of sexual and mental health issues, homelessness, suicide, self-harm and drug and alcohol misuse among this population.

Poorer health outcomes are also higher in Aboriginal and Torres Strait Islander young people than among other Australians, including in the area of sexual health. Indigenous Australians have substantially higher rates of STIs, BBVs and teen pregnancy than non-Indigenous Australians, particularly for chlamydia, gonorrhoea, infectious syphilis, hepatitis B and hepatitis C.<sup>4</sup>

## Phases of the project

Initially designed as a three-tiered project with interventions to occur concurrently

each year across regional and rural Victoria, Mind The Gap initiatives included the Sexual Health & Diversity Enterprise (SHADE), Q&A Emerging Youth GLBTIQ Leaders program and the Mind The Gap social networking site.

## SHADE workshops

The SHADE campaign helped raise awareness about the importance of prevention and testing for STIs and BBVs in young GLBTIQ, Aboriginal and non-Aboriginal people, while supporting greater access to sexual health care through a small community grants program. The campaign included workforce development workshops for health care workers.

These workshops aimed to improve the cultural competency of practitioners working with clients from sexual minorities, with a view to improving access to local services for GLBTIQ youth, and reducing the disproportionate burden of disease – including the risk of HIV transmission.

Organisational culture, the lack of adequate resources and time were identified as the main barriers affecting the ability of participants and their workplaces to respond more effectively to the needs of sexual minorities. These workshops were effective in increasing health care workers' understanding of the effects of stigma and discrimination experienced by sexual minorities and the importance of communicating more effectively with sexual minorities.

## Leadership program

The Q&A Emerging Youth GLBTIQ Leadership program nurtured the leadership capacity of young people – providing them with knowledge about their community together with leadership skills to deal with issues and challenges associated with their progression into leadership roles. This adaptive program was delivered through a combination of experiential learning, community visits, readings, personal reflections, practical engagement and mentoring over a three to four month period.

The program evaluation provided strong evidence that participation had yielded durable effects and lasting impacts on the young people's ability to take on new challenges and leadership roles, enabling them contribute to the wider community as emerging young LGBTIQ leaders.

### Online engagement

The third tier was a Mind The Gap social networking site created to connect emerging leadership alumni from the Q&A program across the years in an attempt to facilitate continued influence, social action and change, as well as to provide an avenue for alumni to support one another. It was designed so that participants could share information, stories, updates and ideas. The Facebook page was set up as a closed network so that frank and fearless conversations could be had between participants in as safe as space as possible in an online context. The page had over 150 members, with about a dozen active contributors to the page.

Both the Q&A and SHADE campaign have been standout components of this program, with 40 young leaders completing Q&A – four of those being Aboriginal and Torres Strait Islander youth. The number of SHADE community grants awarded increased in number over the life of the program with twenty-seven applications received in 2012, compared to eight applications received in 2010.

Over 2010–2012, the SHADE program distributed over \$123,000 in funding for community grants to more than 43 Victorian community organisations. Regions covered included Gippsland, Hume, Victorian Western Districts (Barwon South-West and parts of the Loddon Mallee).

SHADE distributed 50,000 resources and generated over 30 individual media articles about local SHADE events. Alongside this, the workforce development workshops increased both the number of workshops conducted across time and also diversified the breadth of health care workers involved in the training.<sup>5</sup>

### Project outcomes

Mind The Gap had the greatest success in reaching Aboriginal and Torres Strait Islander youth through the SHADE community grants campaign, which received positive feedback from participants and project staff.

The campaign saw an increase in participation from Aboriginal organisations as it offered the chance for community organisations to undertake their own sexual health and diversity initiatives outside more traditional government funding streams, which are often out of reach for such organisations.

One important design feature of SHADE was to ensure that the application process was very much streamlined and supported by Mind The Gap staff, to overcome resourcing barriers relating to time and skills needed to pull together applications for funding.

Events ranged greatly in size, from a small BBQ celebrating diversity – with 10 participants, to a 'Health For Life' consortium instigated by the Mildura Aboriginal Corporation – which attracted 3,000 attendees and 293 STI screenings were conducted on the day.

This year has seen some innovative activities and events, including the 'Think About It' Multimedia Project. Instigated by Uniting Care Cutting Edge, Shepparton, the project centers on a travelling exhibition of videos/photo stories of 10 people (including at least one transgender and one Aboriginal young person). The young people's stories capture all elements of their lives with a strong focus on sexual health and diversity. Their aim is to safely share their stories and 'voices' in the hope that the broader community may learn something and walk away 'thinking about it'.

Another example was a JOY radio event, which was broadcast from Bendigo. The special outside broadcast was committed to showcasing and promoting local services and community engagement. The broadcast aimed to increase awareness around sexual diversity and sexual health in the Loddon Mallee Region and beyond.

The 2013 broadcast event was marketed as a sexual health information forum for same sex attracted youth and their social networks in regional Victoria. Through the array of guests, JOY FM promoted STI and BBV prevention and testing and supported greater access to sexual health care. The broadcast was not only available to those who attended the event, but to young people who may not be comfortable being 'out' or who may be isolated and could listen via radio, online, or via JOY 94.9's smart phone applications.

Extra funding has been allocated to Mind The Gap this year, with a focus on the successful SHADE community grants and workforce development workshops, which are unique in their facilitation of community-owned initiatives tailored to local community environments and based on the communities' needs.

The funding is supportive of the work that needs to be done to create better sexual health outcomes among young people who live in rural and regional areas, as well as highlighting diversity issues and the disparity in the burden of disease carried by GLBTIQ and Aboriginal and Torres Strait Islander young people.

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# What is the role of HIV and STI point-of-care tests in remote Aboriginal and Torres Strait Islander communities?

By James Ward<sup>1,2</sup>, Lisa Natoli<sup>2,3</sup>, Louise Causer<sup>2</sup>, John Kaldor<sup>2</sup> and Rebecca Guy<sup>2</sup> on behalf of the TTANGO Investigator Team

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Sexually transmissible infection (STI) and HIV point-of-care tests (otherwise known as rapid tests) can be used at patient visits to test for STIs and HIV, rather than sending off a sample to the laboratory and waiting for the results. Point-of-care tests provide advantages. They can:

- improve immediate clinical decision making;
- result in better compliance for hard to reach patients;
- reduce loss to follow-up; and
- be used for outreach, and remove pathology access barriers in some remote or rural settings.

There are also some potential challenges of using point-of-care tests:

- They may increase workload for clinicians;
- They may not be as accurate as standard laboratory tests; and
- They require systems to be set up to ensure the tests are being done correctly – quality management.

While lateral flow or ‘dipstick’ devices similar to pregnancy tests are the most familiar point-of-care tests, a range of other tests are also available that can be used at the point of care. According to the World Health Organization (WHO) ‘ASSURED’ criteria<sup>1</sup>, an ideal point-of-care test should be:

1. affordable
2. sensitive (few false negatives)
3. specific (few false positives)
4. user-friendly
5. robust and rapid
6. equipment free
7. deliverable to those who need them.

Thus, introduction of HIV and sexually transmissible infection (STI) point-of-care tests in any setting needs careful consideration of the potential benefits in the target population.

In this article we discuss the role of HIV and STI point-of-care tests in remote Aboriginal and Torres Strait Islander communities.

## HIV point-of-care tests

Lateral flow HIV point-of-care tests are used in most resource limited settings and also some resource rich settings to improve access to HIV testing and HIV treatment. In Australia, there was limited use of HIV point-of-care tests until 2011, when policy restrictions to point-of-care HIV testing in Australia were removed<sup>2</sup> and the Determine™ HIV Combo assay (Alere Pty Ltd, Sinnamon Park, Queensland, Australia), a fourth generation rapid test incorporating antibody and antigen components<sup>3</sup>, was licensed in Australia by the Australian Therapeutic Goods Administration (TGA) for screening<sup>4</sup>. The Determine™ HIV Combo test is licensed for screening only, and any reactive result requires confirmation by standard HIV tests at the laboratories.

Two other tests currently under consideration by the TGA are OraQuick® Advance HIV-1/2 Antibody Test and Uni-gold™ RHT. The reason for the policy change in Australia is the number of people diagnosed with HIV is increasing each year, particular among gay and other men who have sex with men. One of the key ways to reduce HIV transmission is to get people at risk tested early and frequently. However, data from surveys and clinics show that the uptake of testing is less than ideal in Australia.

Some community, clinical, research and government organisation in Australia are now offering HIV point-of-care tests to gay and other men who have sex with men in various settings: community organisation, clinics, and community events.

Although Australia has high quality HIV testing through laboratories, the availability of HIV rapid testing may overcome some of the known barriers to accessing HIV testing such as returning for a result, and the inconvenience of attending clinics<sup>5</sup>, therefore resulting in more infections being diagnosed, and people receiving treatment sooner. HIV point-of-care tests work best when they are used in populations where there is a high HIV prevalence such as in gay men and other men who have sex with men. For example, based on data from the Sydney Rapid HIV Test Study<sup>6</sup> using the Determine™ HIV Combo in a clinic population where 10,000 gay and other men who have sex with men are tested for HIV at current diagnosis rates there will be 100 reactive point-of care tests: of which 66% will be correct (the person does have HIV) and 34% will be incorrect (false positive). In summary, for every two HIV infections detected, there will be one false positive point-of-care result.

## HIV point-of-care tests: use in remote Australia?

The use of HIV point-of-care tests in a low HIV prevalence population such as remote Aboriginal and Torres Strait Islander communities with the Determine™ HIV Combo test will result in a very high number of false-positives. For example, if 10,000 HIV tests are conducted in remote Aboriginal communities in a year (or 100,000 in ten years), at current diagnosis rates<sup>7</sup> there will may be three HIV infections diagnosed in ten years, but along the way, 600 false positive point-of-care results. False positives in this setting will create unnecessary workload for health services, could erode confidence in the point-of-care test and potentially inflict harm on individuals and communities. As any

reactive point-of-care test needs to be confirmed by standard laboratory tests, patients in these remote settings may need to wait weeks to find out that in nearly all cases they do not have HIV.

### **Chlamydia and gonorrhoea point-of-care tests**

Whilst lateral flow point-of-care tests for chlamydia and gonorrhoea have been available for a number of years, their widespread implementation has been constrained by their inaccuracy – meaning the tests will often miss cases of infection (poor sensitivity) but also result in false positive diagnoses (poor specificity) and also most are hard to do with too many steps.<sup>8–10</sup> However, a new test called GeneXpert® has become available, and recently received TGA approval, that uses molecular detection methods (much like the methods used in laboratory) within disposable cartridges and a self-contained instrument that provides point-of-care technology, albeit at a higher cost than lateral flow. The GeneXpert® simultaneously tests for chlamydia and gonorrhoea.

The GeneXpert® has been evaluated in Australian laboratories and field settings in Australia and the United States; evaluations have demonstrated that the test works as well as current laboratory tests.<sup>11,12</sup> The technology will revolutionise point-of-care testing for chlamydia and gonorrhoea. The GeneXpert® can be used to test both urine and swab specimens and is easy to use. Once urine or swabs have been collected from patients it takes about one minute to prepare the specimen (which is inserted into a test cartridge and put into the machine) which provides a result within 90 minutes. The results appear on the computer screen as ‘Detected’ or ‘Not detected’ for each infection (chlamydia or gonorrhoea). The same instrument (GeneXpert®) is recommended by the WHO for diagnosis of tuberculosis (TB), which affects millions of people globally, and in countries which have machines for TB there is the potential for the machines to be also utilised for testing for STIs.

### **Chlamydia and gonorrhoea point-of-care tests: use in remote Australia?**

Currently, we are trialling the GeneXpert point-of-care test, developed by Cepheid, for both chlamydia and gonorrhoea

detection in 12 remote communities in Western Australia, South Australia and Queensland. This is the first use in the world of the GeneXpert® point-of-care test in routine clinical practice. The name of this randomised controlled trial with a crossover design is TTANGO (Test, Treat and Go). What we are hoping to achieve is a reduction in transmission of chlamydia and gonorrhoea in the community and a reduction in repeat chlamydia and/or gonorrhoea reinfections. Mathematical modelling has demonstrated such public health benefits are possible if we can give people access to tests results on the same day as their clinic visit, and if positive, they are given antibiotics immediately.<sup>13</sup>

The average time to treatment in many remote Aboriginal communities is 21 days (compared to three days in urban centres) and only 85% of people who tests positive receive treatment.<sup>14</sup> The GeneXpert® point-of-care test has the potential to reduce the time to treatment to zero days, and increase treatment uptake to 100%. Knowing the result of the test at the initial consultation could also improve the timeliness of partner notification. Although not being measured in the TTANGO study, we would also expect to see a reduction in the short and longer term complications of untreated chlamydia and gonorrhoea infections<sup>15</sup> which can include pelvic inflammatory disease, ectopic pregnancy and tubal factor infertility<sup>16,17</sup>, and a range of adverse pregnancy and neonatal outcomes<sup>18,19</sup>.

Preparation for the TTANGO Trial has been underway for more than 18 months. This has included lengthy engagement with participating health services, laboratories, community and government organisations (see acknowledgements). We have developed numerous standard operating procedures that are reflected in a training package for health professionals, and a range of support materials (e.g., training manual and posters that detail test procedures).

There has also been a strong focus on ‘quality management’ in TTANGO, to ensure that the high quality of testing that is routinely provided by laboratories is not compromised. Routine laboratory testing will also be maintained during TTANGO, so that concordance of laboratory and GeneXpert® results

can be monitored. The implementation phase of the trial commenced mid 2013 and has gone smoothly. We will also be measuring acceptability of the GeneXpert® from both health centre staff and patient perspectives as well as the cost effectiveness of the tests during the trial.

A molecular point-of-care test for trichomoniasis has also recently been developed by Cepheid and as part of the TTANGO trial we are planning to evaluate its accuracy soon.

### **Syphilis point-of-care tests**

Most commercially available syphilis point-of-care tests are lateral flow and detect treponemal antibody in blood, plasma or serum specimens. In Australia, point-of-care syphilis tests that were commercially available prior to 2010 are TGA approved. The syphilis point-of-care tests are relatively robust and unlike the chlamydia and gonorrhoea lateral flow point-of-care tests, they are easy to use with minimal training. A drop of blood or serum is added to the test strip, followed by a few drops of test diluent, and results are available to be read in around 10–15 minutes. The presence of a coloured test and control line on the test strip indicates a positive result. A number of evaluations in different settings have shown these tests to have good accuracy compared to standard laboratory treponemal reference tests.<sup>20,21</sup> A recent laboratory evaluation in Australia of some of these commercially available syphilis point-of-care tests demonstrated no difference in accuracy between HIV negative and positive people, but the tests tended to be slightly less accurate among early (primary) stage syphilis.<sup>22</sup>

Syphilis point-of-care tests are being increasingly widely implemented as part of screening policies in many countries, particularly in antenatal settings as part of the global strategy to eliminate maternal-to-child-transmission of syphilis (congenital syphilis), where resources and access to laboratory testing is limited and loss to follow up is frequent.<sup>23,24</sup> The major limitation of syphilis point-of-care tests is that most commercially available tests only detect treponemal antibody which remains elevated despite adequate treatment for syphilis. As a result, in high prevalence settings the potential for overdiagnosis and overtreatment



of syphilis, along with other sequelae including significant psychosocial consequences, is substantial.

A new point-of-care test (Chembio DPP® Screen and Confirm) is now available that can simultaneously detect both treponemal and non-treponemal syphilis antibodies as two separate test lines on the same test strip. When interpreted together, a positive treponemal and non-treponemal test line suggests current syphilis infection, while a positive treponemal test line alone suggests past/treated infection. This dual detection system may therefore be able to distinguish active from past treated infection and therefore reduce overdiagnosis and treatment in high prevalence settings, but further studies are required to validate the test in practice.

### **Syphilis point-of-care tests: use in remote Australia**

Given the declining prevalence of syphilis in remote communities in Australia<sup>25</sup>, the benefits of programmatic use of syphilis point-of-care tests in remote Australia are unlikely to be realised. However, syphilis point-of-care tests may have a role as part of an outbreak response strategy to rapidly screen communities and provide immediate treatment to those with a positive result. Results from treponemal only point-of-care tests could be cross checked with available medical records to confirm the positive point-of-care is the result of new, active infection rather than old treated infection, and thereby avoiding unnecessary treatment.

### **Conclusion**

In summary, the use of STI point-of-care tests for chlamydia, gonorrhoea in remote Aboriginal and Torres Strait Islander communities is underway, and results will be available in the next few years on the potential benefits of the test in regards to improved service delivery and reduction in population infections rates, and also acceptability. A test for trichomoniasis should also be a priority to help address the unacceptably high rates of this infection in remote communities. The use of HIV point-of-care tests in remote settings will result in more harm than any benefit, but syphilis point-of-care tests may be useful in certain situations such as in response to outbreaks.



Urine specimen being pipetted into the test cartridge.



A test cartridge loaded into the Xpert machine, ready for testing.

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# Treatment as prevention: what's required to make this a relevant strategy in Aboriginal and Torres Strait Islander communities?

By James Ward

There have been some significant advances in knowledge recently in the HIV field. Of particular significance is the concept that HIV treatment can be used as prevention tool in reducing HIV transmission for individuals, at the community level and even globally. This agenda is more commonly known as 'treatment as prevention' (TasP). So how does this work? Where did this concept arise from and what would need to happen for this to become reality in Aboriginal and Torres Strait Islander communities?

## **TasP as an agenda: recognising what has been done so far and ensuring we keep this up!**

Australian Aboriginal and Torres Strait Islander peoples experience the worst health status of any identifiable group in Australia, and the population remains particularly vulnerable to HIV. New and emerging issues as well as social determinants of HIV raise the level of vulnerability. Despite this vulnerability, the Australian response to HIV over the last thirty years – both Indigenous and non-Indigenous led – has resulted in relatively low and stable rates of HIV among Australia's Aboriginal and Torres Strait Islander population.

Some of the mainstays in HIV prevention thus far have included early recognition by Aboriginal peoples of the potential effect that HIV could have on their communities; the supply of health hardware (needle and syringe programs and condoms); the development and implementation of culturally appropriate health promotion messages such as the internationally-recognised 'Condoman' campaign; the inclusion of dedicated Aboriginal and Torres Strait Islander Sexual Health Workers in communities; and an inclusive policy and partnership approach.

Furthermore, the efforts of peak Aboriginal health organisations including the National Aboriginal Community Controlled Health Organisation

(NACCHO) and its member services, and Indigenous programs in mainstream community organisations like the Australian Federation of AIDS Organisations (AFAO) and its member organisations, have all contributed to prevention success. Efforts need to be maintained, however, to ensure an escalated epidemic does not occur, particularly among heterosexual people, and especially among women, and people who inject drugs.

## **TasP: where did this concept arise from?**

Advocates, researchers and others have used evidence from several recent large clinical trials which have demonstrated that people with HIV who have suppressed or undetectable viral loads – particularly those on treatment – are much less likely to transmit HIV than untreated persons. Specifically, this is based on the knowledge that antiretroviral therapy (ARV) reduces the HIV viral load in blood as well as in genital secretions (for both men and women).

A number of studies have shown that people who are on ARV treatment are less likely to transmit HIV to their partners. One study (the 'Partners in Prevention' study from 2010) showed that heterosexual HIV-positive people on ARV treatment were 92% less likely to transmit the virus to their partners than people who were not taking treatment.<sup>1</sup>

The most important evidence about the efficacy of treatment as prevention arrived in 2011 with results from the HPTN 052 trial. This study demonstrated that for people in serodiscordant relationships (where one partner is HIV-positive and the other HIV-negative) there was a 96% reduction in HIV transmission risk where the HIV-positive partner was on ARV treatment.<sup>2</sup>

Further studies are continuing in this vein to determine the effects of TasP, particularly among gay men – but the

evidence is clear and has been described as a 'game changer' in HIV prevention by Michel Sidibé, Director of UNAIDS.<sup>3</sup>

## **How does TasP work?**

The treatment as a prevention agenda works not only at the individual level but also, importantly, at the community level. The theory works like this: we know that an individual living with HIV who is on ARV and with suppressed and/or undetectable viral loads has minimal risk of transmitting HIV to another person, therefore if everyone with HIV were on effective ARV treatment there would be minimal risk of transmission in the whole community.

## **What does TasP mean for Aboriginal and Torres Strait Islander communities?**

Currently there are about 400 Aboriginal and/or Torres Strait Islander people diagnosed with HIV in Australia.<sup>4</sup> There may be many more undiagnosed cases in the community or maybe not – just as there are in other identified communities. For instance, it is estimated that between 10 and 30% of gay men in Australia are living with HIV but are undiagnosed.<sup>5,6</sup>

To decrease chances of HIV transmission at the individual level and at the community level among Aboriginal and Torres Strait Islander communities, the 400 or so people living with HIV would each need to be on effective ARV. We do not currently know the number of HIV-positive people who are engaged with treatment, so some innovative and sensitive research would be required, as well as a targeted campaign about treatment and its benefits.

To work at the community level it would also mean that everyone in these communities who is living with HIV but is undiagnosed would need to be diagnosed and then commence treatment. One way of doing this is to initiate a national targeted campaign tailored

for the Aboriginal and Torres Strait Islander community as well as a strategy of increased testing within primary and other health services that see Aboriginal and Torres Strait Islander patients. This strategy would need to be balanced and include appropriate pre- and post-test conversations with patients, and effective follow-up and case management. Assuming people living with HIV wish to be on treatment, and that they are actively engaged with their doctors and regular monitoring occurs to ensure the medications are suppressing viral loads, this should work in any context.

Data from the HIV Futures 6 study shows the myriad of complex issues currently faced by who are living with HIV. Firstly, of 1,106 people who completed the survey, 80% were on HIV treatment<sup>7</sup>, meaning another 20% would need to commence treatment for TasP to work in this population. However, for people on treatment who responded to the survey, almost 40% had difficulty in taking them all the time.<sup>8</sup> Common issues that affected adherence included side effects, remembering to take medication on time, transporting medications, taking medications in public and organising meals around medications, as well as the quantity of drugs to be taken.<sup>9</sup> Issues of discrimination, employment, housing were all issues affecting people living with HIV.<sup>10</sup> For Aboriginal and Torres Strait Islander people these issues are impacted further by experiences of racism and discrimination both within and outside the health care system.

Aside from the current gaps in our knowledge to make TasP an appropriate strategy in Aboriginal and Torres Strait Island communities (treatment rates and undiagnosed cases) we would need to look holistically at the treatment and management cascade to ensure TasP can be a success. In doing so, the following are essential for the strategy to work:

- maintaining efforts in addressing the social determinants of health that impact Aboriginal and Torres Strait Islander people disproportionately (poverty, education, housing, employment and racism), because if these are not addressed then it makes it much more difficult for people to be engaged with health services
- a continuation of reducing some of the existing factors that increase vulnerability of HIV transmission within Aboriginal and Torres Strait Island people such as high rates of other STIs and unsafe injecting practices
- continue to promote traditional and proven prevention strategies such as safe sex, condom use and needle and syringe use
- increasing our understanding of the barriers and facilitators of HIV testing and treatment, including medication compliance for Aboriginal and Torres Strait Islander people living with HIV
- increasing the health workforces' capacity to be able to test, diagnose and manage patients within health services free of racism and discrimination and make our health services pathways easy to navigate; from diagnosis to management
- the implementation of health promotion work in the community about the benefits of testing and treatment for HIV.

Finally, in engaging in the treatment as prevention strategy, it will take a coordinated approach – with the communities involved, with government, with academia and non-government organisations to make this happen. This is where we have to start, and we should start, to continue the relatively good news story of HIV in Aboriginal health.

James Ward is an Indigenous health researcher with more than 15 years' experience working within

Aboriginal health and communities in Australia. He is Head of Preventive Health and Deputy Director at Baker IDI, Central Australia, Alice Springs. He is also lead researcher on several current key research studies relating to STIs and reproductive health among Aboriginal and Torres Strait Islander communities, including STRIVE and GOANNA. James is a guest editor of this edition of *HIV Australia*.

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# REGIONAL FEATURE: Nothing about us without us!

## HIV and Indigenous peoples

By Marama Pala (Ngātiawa Iwi)

Looking from outside the regional bubble of the Australian/New Zealand/Pacific Islands countries and territories, some might think that HIV is not an obvious Indigenous health priority. At least, this is how it may appear when viewing epidemiological data. As the co-chair for the International Indigenous Working Group on HIV and AIDS (IIWGHA), I would say that the opposite is true. Complacency, misinformation, stigma and discrimination will be the vehicle that HIV will use to 'ride' in to our community. In addition, the social health determinants of health (education levels, unemployment, income, housing, and racism) places Aboriginal Australia/Canada and New Zealand Indigenous peoples as a vulnerable population to HIV and AIDS.

For 30 years, Indigenous people have been part of the epidemic and have either been not represented or, in some instances, misrepresented or overrepresented in the data. As examples: Indigenous Australians were not accounted for in the first ten years of the epidemic in Australia; and as an example of overrepresentation, rates of HIV diagnosis in Canada among Aboriginal peoples are much higher than for non-Indigenous Canadians and affect population groups quite differently to those in New Zealand and Australia.<sup>1</sup> Among these populations almost 60% of cases of HIV are attributable to intravenous drug use and almost 60% of cases are among women.<sup>2</sup> For Australia and New Zealand, this is an indication of where Indigenous peoples of Oceania could end up – a place that none of us want to get to.

Poor outcomes in the social determinants of health are intrinsically linked to HIV vulnerability. These are issues that Indigenous peoples share in commonality across the globe. Addressing HIV as a stand-alone issue in Indigenous and other vulnerable population groups is futile in many instances. Research that encompasses the social determinants of HIV is as much a priority as HIV clinical trials; both must be ongoing, and should



This image was taken by IIWGHA's Trevor Stratton at AIDS 2012. The drum is a very powerful symbol of healing and good medicine for First Nations people in North America. Superimposed on the drum is the IIWGHA logo, which was developed with the notion of people of the human race joining hands around the world to respond to HIV and AIDS. The red, yellow, red and black colours represent the four families of the human race and a reminder that we are all related.

be thorough and mindful of both cultural and social determinants of health.

In response to the need for continued research and activism in this area, The International Indigenous Working Group of HIV and AIDS (IIWGHA) was formed to provide a vision and a voice that places Indigenous peoples at the centre of the response to HIV. IIWGHA is made up of country leaders that include Aboriginal people living with HIV and other Indigenous champions of the HIV response – including men who have sex with men (MSM), people who inject drugs (PWID), sex workers, women and children.

We have five country leaders in the Oceania region:

### Australia

- Michael Costello – Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA)
- James Ward – Baker IDI, Central Australia.

### New Zealand and the Pacific

- Marama Pala – INA (Māori, Indigenous and South Pacific HIV/AIDS Foundation)
- Dr Clive Aspin – INA (New Zealand) and

- Temo Sasau (formerly of Pacific Island AIDS Foundation) (Fiji).

We each represent marginalised communities; we work with organisations that provide culturally appropriate prevention, care, treatment and support; and advocate in the areas of prevention, treatment, care and support as well as identifying and addressing cultural and social determinants of HIV.

### What are the issues for Indigenous Peoples living in Oceania? Where is our voice?

Too many times our voice, our place in the epidemic, is hidden or swallowed within the 'at risk populations' agenda. For example, men who have sex with men will include Indigenous men who have sex with men; people who inject drugs will include Indigenous people who inject drugs; sex workers will include Indigenous sex workers; women and children will include Indigenous women and children. This means that there is no definition or understanding of the social health determinants that separate us as Indigenous people within the 'at-risk populations'.

Let me explain some of the social health determinants I'm speaking of.

## Indigenous social determinants of health

### Political and social marginalisation

We are the original inhabitants of our lands, yet we lack political power. This places us at a power imbalance on our own homelands; we are always operating on the back foot and any Indigenous initiatives come under minute scrutiny. Poor housing conditions add to our health disparities. All this makes it virtually impossible for us to improve our situation.

### Discrimination

As Indigenous peoples, we are more likely to experience discrimination compared to non-Indigenous people, including when seeking to access: employment; healthcare; housing; welfare support; education; and government (local, state, national). We are consistently the highest population of unemployed, and those who are employed are in low/middle income and have limited healthcare access or consideration.

Neo-colonialism is threatening our ability to address this epidemic in colonised countries.<sup>3</sup> The Patriarchal system that continually places Indigenous people as the 'child' in a parental relationship is a barrier when it comes to 'nothing about us without us'. This highlights the need to bring about social change and inclusion of strong Indigenous leaders at all levels within the HIV sector.

Which leads us to consider the 'academic industrial complex' experienced by Indigenous peoples – in particular women.<sup>4</sup> Historically, academics working in the HIV sector have written documents, policies and guidelines about Indigenous people without full consultation and acknowledgement. Many times these materials have been completely inaccurate; there are very few Indigenous Academics within this sector, again this becomes a 'trust' issue. We trust our sexuality researchers and academics to represent us. But we have very few 'ally' academics in academia. Feminism has also not been kind to Indigenous women. Discrimination comes in many forms for Indigenous peoples.

### Poverty

Poverty is a fundamental social health determinant that places Indigenous

people at significant risk of chronic illness or disease. The Māori population is disproportionately represented in New Zealand's labour market. March 2012 figures from the New Zealand Department of Labour showed that 34% of Māori people were not part of the workforce due to unemployment, child rearing, and other reasons.<sup>5</sup> The median weekly income for people receiving income from government transfers (which includes income from unemployment benefits and paid parental leave) is around \$288 per week.<sup>6</sup>

We operate within generational sole parent communities dependent on the welfare system, which has contributed to discrimination against women and children, low graduation rates in higher educational establishments and lack of parity within government representation.

### Racism

Racism, some would say, is the same as discrimination. But it is more complicated than that for Indigenous populations. Racism comes from a deep-rooted belief system that sees Indigenous people as inferior. Seen from this perspective, Indigenous people are placed at an inherent disadvantage just by being born Indigenous.

### Incarceration

Because of many of the factors discussed above, survival for some of us involves criminal acts. Crime becomes a means of survival – feeding the family or constantly wanting for what we can't afford. As children, for some of us the experience of violence is commonplace in the home and so frequently becomes part of our lives as adults.

Basic life skills can be put aside and become less important than primal survival skills. This means that some of our parents lack the knowledge to teach us basic life skills, but expose us to primal survival skills – skills that we actually do need to survive. A consequence of this skewing of 'skills' is that Māori number 50% or more of the prison population in New Zealand when we are only around 15% of the total population.<sup>7</sup>

### Unmet health needs and distrust in health systems

Health disparities within Indigenous cultures are exacerbated because of a lack

of trust in government services, including health services. Discrimination, racism, institutionalised racism and high prison rates all contribute to this lack of trust.

Māori experience unmet health care needs more frequently than any other population group in New Zealand; in the 2011–12 period, two in five (39%) Māori adults had unmet primary health care needs – rates that are 1.5 times higher than the those found among the non-Māori population.<sup>8</sup>

Life expectancy is significantly lower for Indigenous people compared to non-Indigenous people. According to Statistics New Zealand, life expectancy at birth is 76.5 years for Māori females and 72.8 years for Māori males, compared with 83.7 years for non-Māori females and 80.2 years for non-Māori males.<sup>9</sup>

Accurate health data collection is highly problematic. Many Māori in the 1980s through to today would prefer not to be recorded as a New Zealand Māori, just in case this places us (individually) at a disadvantage – again, a trust issue. Also, some of our population has been diluted so much that many who identify as Māori may have a physical appearance of being non-Māori, which can lead to inaccurate data collection.

### Mental health and addictions

Globally, Indigenous peoples factor highly in the mental health and addictions statistics. It is here we find the combination of the 'mistrusts' cited above and internal issues of 'family', where we find embedded behaviours of physical and sexual abuse.

Theorists have come up with possible reasons for abuse within Indigenous communities. These are numerous, but broadly include:

- that the thread of Indigenous societies has unraveled through the introduction of religion and nuclear families
- that the continual disempowerment of our men and women results in high rates of child abuse, child deaths, male assaults on women
- secrecy regarding incest and sexual abuse within the home. This can be deeply embedded and relates not only on the abusive act itself, but also to the perceived ability to have



'power' over an individual through fear and abusive trust because of the perpetrator's own perceived feelings of disempowerment – linked again to colonisation.

- introduced belief systems that define homosexuality as a sin, damaging Indigenous people throughout the world. I can only mention my own people, where, prior to colonisation, same-sex relationships were accepted and these individuals were even revered as holding the spirit of both male and female. For Māori, such individuals were considered doubly blessed and treasured within our community. So too were those with mental illness (today's definition); our perception of people displaying the ability to speak to spirits and gods as truly 'touched' by the gods has been eclipsed.

Next, consider HIV and Indigenous populations. Wrap up all the 'birth right' social health determinants listed above, then add in stigma and discrimination based on fear and ignorance of 'another' introduced pathogen. What are we left with? A very complex population facing a considerable threat.

### What can IIWGHA do?

The concept of IIWGHA reaches back to 1988, where key people met and formed a network between the countries based on the common factors between each land. It is the first of its kind to specifically address HIV and AIDS for Indigenous populations.

We work at creating relationships between governments, Indigenous leaders, researchers and HIV/AIDS organisations. Regionally, we are working together with government, leaders, researchers and HIV/AIDS organisations to hold an Indigenous Pre-conference in July 2014 in Sydney, in the lead-up to the International AIDS conference in Melbourne. IIWGHA meets regularly via Skype calls at least six times per year and also meets face-to-face whenever possible. Members will be traveling to Saskatoon in Central Canada in September for a research conference and meeting to plan the next five years of research projects for IIWGHA. At every International AIDS Conference

since 2006, IIWGHA has held a pre-conference focusing on Indigenous people and HIV. This has helped raise the visibility of Indigenous peoples within the context of the epidemic.

Regionally, as we prepare for AIDS 2014, I am participating on the Community Program Committee of AIDS 2014. This is my second term on this committee. My first was with AIDS 2012 in Washington, DC.

Within our region we are also committed to increasing knowledge and addressing the stigma of HIV and AIDS within our Indigenous communities and supporting Indigenous-directed research and awareness initiatives by supporting the national Indigenous NGOs in their partnerships with non-Indigenous AIDS organisations and governments. First Nations Inuit Health and Health Canada, and governments in the USA and Australia, have supported us financially. We have also received support from ViiV Healthcare Canada and MAC AIDS Fund.

We have 17 leaders from 11 countries including: Australia, Bolivia, Canada, Chile, Ecuador, Fiji, Guatemala, Mexico, New Zealand, Peru and USA. We have two important policy documents – *The Toronto Charter: Indigenous Peoples' Action Plan on HIV/AIDS 2006*<sup>10</sup> and the *International Indigenous Strategic Plan on HIV & AIDS For Indigenous Peoples and Communities from 2011–2017*<sup>11</sup>.

We attended the United Nations permanent forum on Indigenous issues this year, holding our own side event to bring HIV awareness to this arena. We had a presence at the International Health Promotion and Education Conference in Pattaya, Thailand recently, informing participants about our contribution to the fight against HIV/AIDS.

In September 2013, we met in Australia with government, community leaders and NGOs in preparation for the 2014 Indigenous Pre-conference, to be held prior to the International AIDS Conference.

To define our mission and vision simply, would be to acknowledge and adapt the GIPA principles and slogan for Indigenous Peoples – Nothing about us without us!

Marama Pala is Executive Director of INA (Māori, Indigenous and South Pacific) HIV/AIDS Foundation in New Zealand and Co-Chair of the International Indigenous Working Group on HIV and AIDS (IIWGHA). She is also a member of the Community Program Committee of the 20th International AIDS Conference (AIDS 2014); the Co-chair of the Global Village and Youth Pavilion Working Group. Marama is a Māori Indigenous woman who has been living with HIV for 20 years.

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## BOOK REVIEW: CONDOMAN AND LUBELICIOUS

Since the late 80s, the Aboriginal community has worked tirelessly to find effective models of education for use in the community that give clear and concise health promotion messages. Condoman and Lubelicious is the second comic book in a series that deals with the difficult topic of HIV and sexual health in our communities.

The concept of Condoman was first designed and developed in North Queensland in the early 90s by a very talented and dedicated woman by the name of Gracelyn Smallwood. Her aim was to create a superhero character that would spread safe sex messages and education about HIV and sexual health in Aboriginal and Torres Strait Islander communities in Queensland. This led her to create Condoman, a caped crusader superhero decked out in Aboriginal colours; a character designed to be used by Aboriginal and Torres Strait Islander Health workers to provide an engaging form of health promotion.

The process of creating the story for the comic involved running workshops with Indigenous people in Brisbane. This helped to ensure that the comic is culturally appropriate and engaging. The style of language is effective and culturally correct – in both English and Aboriginal English, with a small amount of Torres Strait Islander Creole. The language used is fluent and engages the reader with many thought-provoking storylines. Descriptive language is used to provide detail of specific and sometimes difficult areas to address in sexual health education and prevention and in overall community health.

It is excellent to see the Spiritual Leaders depicted throughout the comics. This imagery of spiritual leaders from the First Peoples of the world gives a very



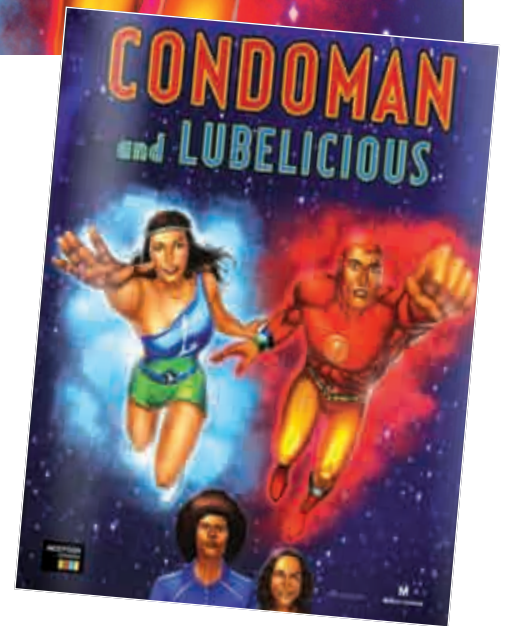
significant cultural tone to the comic, and gives it the ability to reach many in the target populations – and also lends the comic for use in international settings in the future. It is also great to see Condoman and Lubelicious superhero suits in both the Aboriginal and Torres Strait Islander colours; this automatically attracts the target population.

The information provided about each sexually transmitted infection is current and clear and provides good, thought stimulating information that can lead our people to be correctly informed. I really like the concept of sexually transmitted infections having aliases, as this shows the fact that these infections can be dormant and deceitful and can take on many disguises ... the comic uses an equal mix of male and female figures to show that STIs are not sexually biased.

The comic also provides accurate information to help individuals make good informed choices about risk behaviours, whether they be sexual or about recreational drug and alcohol use.

The fact that Condoman and Lubelicious are 'normal' people in the community that can morph into superheroes to combat all forms of sexually transmitted infections is brilliant, and shows that anyone in the community can take responsibility to help fight for the eradication of sexually transmissible infections through good, sound health education and health promotion.

In closing, I believe that these comics should be funded at a national level (by the Commonwealth) to be utilised in sexual health education and promotion in schools, youth centres and health centres for the whole Australian population.



Congratulations to all the talented people at Queensland Association of Healthy Communities (QAHC), Queensland Aboriginal and Islander Health Council (QAIHC) and Inception Strategies who worked so hard to develop such an informative and engaging health promotion resource!

**Reviewed by Neville Fazulla**, gay community member. The views expressed in this column are the personal views of the author.

Neville Fazulla is an Indigenous Australian with an extensive and varied career working with and representing Indigenous and gay communities. Over 21 years he has held staff or Board positions at organisations including Aboriginal Health and Medical Research Council of New South Wales, the Aboriginal Health Council of South Australia, the AIDS Council of South Australia, Queensland AIDS Council, People Living with HIV/AIDS South Australia, National Association of People Living with HIV Australia, Australian Federation of AIDS Organisations and many others. He has also been a community representative and spokesperson on numerous steering committees and community networks around the country.





## TREATMENT BRIEFS

### NEW TENOFOVIR FORMULATION WORKS EQUALLY WELL WITH LESS EFFECT ON KIDNEYS AND BONES

By Liz Highleyman. Produced in collaboration with [hivandhepatitis.com](http://hivandhepatitis.com)

Tenofovir alafenamide (TAF), a new formulation that produces higher drug levels in cells but allows for lower dosing, was as effective as the current tenofovir disoproxil fumarate (TDF) formulation, but had less impact on markers of kidney function and bone turnover, researchers reported at the 53rd Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC), held 10–13 September in Denver.

Tenofovir is one of the most widely used antiretroviral drugs. It is highly effective and generally regarded as safe and well-tolerated. However, it can cause kidney toxicity in some individuals and is associated with bone loss that begins soon after starting treatment. The long-term consequences of these side-effects are a growing concern in light of guidelines recommending earlier treatment initiation and expanding use of *Truvada*<sup>®</sup> (which contains TDF) for pre-exposure prophylaxis (PrEP).

Gilead Sciences' new TAF formulation produces fivefold higher concentrations of active tenofovir diphosphate in cells that harbour HIV, but drug levels in the blood remain much lower compared with TDF. This enables reduced dosing that is expected to have a less detrimental effect on the kidneys and bones.

Paul Sax from Brigham and Women's Hospital in Boston presented late-breaking results from a phase 2 study comparing TAF at 10mg and TDF at 300mg, both as part of a single-tablet regimen that also includes the integrase inhibitor elvitegravir, cobicistat (a pharmacoenhancer or 'booster') and FTC (emtricitabine). The TDF-containing coformulation is marketed as *Stribild*<sup>®</sup>; the TAF version is not yet approved.<sup>1</sup>

This double-blind, placebo-controlled trial included 170 previously untreated people with HIV who were randomly assigned (2:1) to receive the TAF or TDF coformulations once-daily for 48 weeks.

Almost all participants were men, more than two-thirds were white, nearly one-third were black and the median age was about 35 years. The median baseline CD4 cell count was about 390 cells/mm<sup>3</sup> (though about 15% had less than 200 cells/mm<sup>3</sup>) and the median viral load was approximately 40,000 copies/ml. At study entry participants had normal kidney function, with a median estimated glomerular filtration rate (eGFR) of 115 ml/min. People with hepatitis B or C co-infection were excluded.

At this year's Conference on Retroviruses and Opportunistic Infections (CROI 2013), Andrew Zolopa reported 24-week interim data from the study, showing that 87% of people taking the TAF coformulation achieved HIV RNA below 50 copies/ml compared with 90% of those taking *Stribild*<sup>®</sup>.

The TAF and TDF coformulations were both generally safe and well-tolerated, with most side-effects being mild or moderate. Most adverse events occurred at similar rates in both groups, but nausea was nearly twice as common in the TAF arm (21 vs 12%). There were no treatment-related serious adverse events in either arm.

Laboratory abnormalities were also generally comparable in the two treatment arms. However, more people in the TAF arm had abnormally high low-density lipoprotein (LDL or 'bad cholesterol'). Sax explained that tenofovir has a lipid-lowering effect in the blood, but this didn't happen to the same extent with TAF because its plasma concentration is so much lower.

In relation to kidney function, there was less change in eGFR over time in the TAF coformulation arm compared with the *Stribild*<sup>®</sup> arm (-5.5 and -10.0, respectively). Sax noted that other indicators of kidney function also favoured the TAF coformulation. No cases of renal tubulopathy were seen in either study arm and nor did anyone discontinue therapy due to kidney-related side-effects.

Looking at bone loss, bone mineral density (measured by DEXA scans taken at 24 and 48 weeks) decreased less in the TAF arm than in the TDF arm

at both the spine (-1.00 vs -3.37) and the hip (-0.62 vs -2.39). Furthermore, one-third of participants taking the TAF coformulation experienced no change in hip bone density compared with just 7% in the *Stribild*<sup>®</sup> arm.

Biomarkers of bone resorption and bone formation favoured TAF over TDF (procollagen type 1 N-terminal propeptide: 109 vs 169%; C-terminal telopeptide: 119 vs 178%). No fragility fractures occurred in either arm of the study.

Treatment-naïve participants taking the TAF coformulation had high levels of viral suppression over 48 weeks, comparable to those seen with *Stribild*<sup>®</sup>, the researchers summarised. But people taking the TAF coformulation had a smaller decrease in eGFR and significantly smaller decreases in bone mineral density of the hip and spine.

Sax said that phase 3 studies are underway and researchers are making an 'aggressive attempt' to enrol more women.

### Reference

1. Sax, P. et al. (2013). 48-week study of tenofovir alafenamide (TAF) versus tenofovir disoproxil fumarate (TDF), each in a single tablet regimen (STR) with elvitegravir, cobicistat, and emtricitabine [E/C/F/TAF vs. E/C/F/TDF] for initial HIV treatment. 53rd Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC), Denver, abstract H-1464d, 2013.

Adapted from [www.aidsmap.com](http://www.aidsmap.com)  
Published: 13 September 2013

### RALTEGRAVIR IS A GOOD CHOICE FOR PEOPLE WITH HIV UNDERGOING CANCER CHEMOTHERAPY

By Liz Highleyman. Produced in collaboration with [hivandhepatitis.com](http://hivandhepatitis.com)

The integrase inhibitor raltegravir may be an optimal choice for many HIV-positive people receiving cancer chemotherapy, as it is highly effective and well-tolerated in this population, according to a poster presentation at ICAAC.<sup>1</sup>

A growing body of evidence indicates that people with HIV have a higher risk for several AIDS-defining and non-AIDS malignancies, but approaches for treating cancer in this population have not been extensively studied.

Harry Torres and colleagues from the University of Texas MD Anderson Cancer Center in Houston conducted

a retrospective analysis of different antiretroviral regimens used by HIV-positive adults receiving cancer treatment at their hospital.

The study – which may be the largest series analysing the effectiveness of antiretroviral therapy (ART) in people with HIV undergoing cancer chemotherapy<sup>2</sup> – looked at medical records of 154 eligible patients with any type of cancer seen at the centre between January 2001 and December 2012.

Most of the study participants (80%) were men and about half were white. Only people who made regular visits (at least twice in a six-month period) were included. The most common type of cancer was haematological malignancies such as lymphoma and leukaemia, accounting for 58% of all cases; 42% had non-Hodgkin's lymphoma, an AIDS-defining cancer. Amongst people with solid tumours, the most common was gastrointestinal cancer, in 31%.

Participants received ART regimens that included a protease inhibitor (37%), a non-nucleoside reverse transcriptase inhibitor (NNRTI, 32%), an integrase inhibitor (only raltegravir was approved, 19%) or a combination of these (11%), along with optimised nucleoside/nucleotide reverse transcriptase inhibitor (NRTI) 'backbones'.

Oncologists, pharmacists and infectious disease specialists reviewed regimens to minimise drug-drug interactions. ART efficacy was defined as absence of virological failure (HIV RNA >200

copies/ml for six months or more) or virological rebound (>200 copies/ml after viral suppression).

Raltegravir was the most commonly used antiretroviral drug amongst people with haematological malignancies. More people taking raltegravir (46%) were antiretroviral-naïve at the time of cancer diagnosis.

Raltegravir was also favoured by people using high-dose steroids and specific anti-cancer medications including topoisomerase inhibitors, alkylating agents and anti-metabolite drugs. No significant differences among antiretroviral classes were seen for people using other types of cancer therapy including cytotoxic agents, vinca alkaloids, anti-tumour antibodies, corticosteroids or radiation therapy.

Antiretroviral efficacy was similar for integrase inhibitors and non-nucleoside reverse-transcriptase inhibitors (NNRTIs) (96% vs 97%), both of which worked significantly better than protease inhibitors (65%). People treated with raltegravir were six times more likely, and those taking NNRTIs were nine times more likely, to achieve sustained HIV suppression compared with those taking protease inhibitor-based regimens, according to a multivariate analysis.

Side-effects were more than twice as common with protease inhibitors (35%) compared with NNRTIs (14%), which in turn caused more side-effects than raltegravir (3%). Mortality was also significantly higher amongst protease inhibitor or NNRTI recipients

(46 and 36%, respectively) compared with raltegravir recipients (13%).

ART interruption was less common amongst raltegravir recipients (7%) compared with those taking protease inhibitors or NNRTIs (28 vs 26%). Clinically relevant drug-drug interactions were seen only in people using protease inhibitors.

ART regimens that included protease inhibitors were the 'least favourable' for HIV-positive cancer patients, the researchers concluded. NNRTIs and integrase inhibitors had 'comparable efficacy', but based on safety, integrase inhibitors (i.e., raltegravir) 'appeared to be the antiretroviral of choice' for HIV-positive patients with haematological malignancies or those receiving various chemotherapeutic agents.

They recommended that prospective studies be done to further define toxicity profiles in HIV-positive cancer patients receiving chemotherapy, and such studies should aid the development of guidelines for treatment of this population.

## References

1. Torres, H., et al. (2013). *Efficacy and safety of antiretrovirals in HIV-infected patients with cancer*. 53rd Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC), Denver, abstract H-1255.
2. ICAAC/American Society for Microbiology Antiretroviral Drugs in HIV-infected Patients with Cancer. (2013.) Press release, September 12.

Adapted from [www.aidsmap.com](http://www.aidsmap.com)  
Published: 13 September 2013



## Vale Malcolm Leech (1956–2013)

### Ambassador, Hep C and HIV Community Advocate, Colleague, Friend.

It is with great sadness that we note the passing of Malcolm Leech at 12:35am on Friday 20 September from cancer at the Sacred Heart Hospice, Darlinghurst, age 57.

Malcolm made a significant contribution in many areas of life, including theatre and community. He was a strong advocate for people living with HIV, a positive speaker, and Director, Secretary and past President of Positive Life NSW (2006 to 2012). Malcolm also served on the Board of the Bobby Goldsmith Foundation from 2008–2010 and a variety of community theatre boards, including being a founding member of the Carriageworks Board. Malcolm will be very much missed by the Board and Staff of Positive Life NSW.

Our thoughts go out to Malcolm's friends and loved ones at this time.



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### ● **October**

21–23

#### **2013 Australasian HIV & AIDS Conference (25th Annual Conference of the Australasian Society for HIV Medicine)**

Darwin, Australia  
[www.hivaidsconference.com.au](http://www.hivaidsconference.com.au)

23–25

#### **2013 Australasian Sexual Health Conference**

Darwin, Australia  
[www.shconference.com.au](http://www.shconference.com.au)

30–31

#### **4th International Workshop on HIV & Ageing**

Baltimore, MD, USA  
[www.virology-education.com](http://www.virology-education.com)

### ● **November**

13

#### **What do we think shapes sexual risk-taking in gay men? (CSRH Seminar Series)**

Sydney, Australia  
<https://csrh.arts.unsw.edu.au>

17

#### **APCOM MSM and Transgender Pre-conference**

Bangkok, Thailand  
<http://www.apcom.org/apcom-pre-conference-registration>

18–22

#### **The 11th International Congress of AIDS in Asia and the Pacific (ICAAP11)**

Bangkok, Thailand  
[www.icaap11.org](http://www.icaap11.org)

18–19

#### **ICAAP Community Forum**

Bangkok, Thailand  
<http://icaap11.org/index.php/community-programme/community-forum>

### ● **December**

3–6

#### **6th International Workshop on HIV Persistence, Reservoirs and Eradication Strategies**

Miami, United States of America  
<http://www.informedhorizons.com/persistence2013>

7–11

#### **17th International Conference on AIDS and Sexually Transmitted Infections in Africa (ICASA 2013)**

<http://www.icasa2013southafrica.org>

## 2014

### ● **January**

13–14

#### **4th International Workshop on HIV & Women – From Adolescence through Menopause**

Washington, United States of America  
<http://www.virology-education.com>

### ● **February**

20–21

#### **13th Social Research Conference on HIV, Viral Hepatitis and Related Diseases – Promises & Limitations**

Sydney, Australia  
<http://hhard.arts.unsw.edu.au>

### ● **March**

18–21

#### **7th SAHARA Conference 2014 (SAHARA 7)**

Dakar, Senegal  
[www.sahara.org.za/conferences/2013](http://www.sahara.org.za/conferences/2013)

# Diary

# INTERNATIONAL INDIGENOUS PRE-CONFERENCE ON HIV & AIDS SYDNEY 18 & 19 JULY 2014

AN **AIDS 2014** AFFILIATED INDEPENDENT EVENT

**The International Indigenous Pre-conference on HIV & AIDS will take place in Sydney, Australia prior to the International AIDS Conference in Melbourne. The two-day pre-conference will bring Indigenous experts from around the world to network, transfer knowledge and share best practices.**

The International Indigenous Working Group on HIV and AIDS (IIWGHA) in partnership with the Australian Aboriginal Organising Committee (AAOC) aims to 'create an international voice and structure that links Indigenous peoples with their Indigenous leadership, varying levels of governments, AIDS service organisations, cooperatives, and others in a global collective action to lower the disproportionate impact of HIV and AIDS experienced by Indigenous peoples.'

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[iiwgha.org](http://iiwgha.org) or [ana.org.au](http://ana.org.au)**



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