



HIV AUSTRALIA

**Leading through Partnership:
The community response to HIV**

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AFAO's aims are to:

- Advocate on behalf of its members at the Federal level, thereby providing the HIV/AIDS 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/AIDS;
- Develop and formulate policy on HIV/AIDS 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/AIDS and its effects.

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AFAO is the peak non-government organisation representing Australia's community-based response to the epidemic of HIV/AIDS. AFAO's members are the state and territory AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Injecting and Illicit Drug Users League, Scarlet Alliance and the Anwernekenhe National Alliance.

On the cover Professor Michael Kidd, Chair of a new Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections (MACBBVS), speaks with **HIV Australia Editor Abigail Groves**. See page 12.

We want to hear what you think about

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HIV Australia welcomes suitable reports from interested authors. To submit an idea or report for consideration, email editor@afao.org.au



LOCAL NEWS

Gay blood donation ban “not discriminatory”

The Tasmanian Anti-Discrimination Tribunal ruled on 27 May 2009 to uphold the current blanket gay blood ban by the Australian Red Cross Blood Service (ARCBS). After reviewing a “vast volume of evidence” and assisted by “clear, comprehensible and comprehensive” presentations by complainant Michael Cain and the ARCBS, the Tribunal dismissed Mr Cain’s claim of discrimination on the basis that the ARCBS has a legal obligation to ban gay donors and because, in the absence of conclusive data on the risk associated with low-risk gay sex, the ARCBS must act on “the worst case scenario.”

In October 2004, Mr Cain offered to donate his blood in Launceston, Tasmania. However, current guidelines prohibit gay men who have had sex in the last twelve months to donate blood, due to “the risk of an undiagnosed HIV infected donation ... which may not be picked up with routine testing of the blood during the early stages of infection.”

Mr Cain launched a complaint leading to an inquiry from August to November 2008, where he argued that “homosexual men who are in stable, monogamous relationships and practice safe sex, should be permitted to donate blood as this would not put the blood supply at risk. Instead, on the positive side, it would provide a new source of blood and facilitate the altruistic motivations of those donors and do away with unwarranted discrimination.”

Regardless of the outcome of the decision, the Tribunal has been urged to consider the substantive issue of whether the policy is discriminatory. Mr McCain has vowed to continue his campaign.

New Research Centre for Aboriginal Health

The Rudd Government will provide \$2.5 million to establish a Centre for Clinical Research Excellence in Aboriginal Health at the University of New South Wales, announced in April. The funding will help researchers to determine the incidence of HIV in Indigenous communities and investigate the best ways to identify and treat HIV and other blood-borne viruses (BBVs) and sexually transmitted infections (STIs).

Developing a better understanding of when and how these infections develop in Aboriginal people has the potential to improve the health of Indigenous communities and assist in reducing the 17 year life expectancy gap between Indigenous and non-Indigenous Australians. The grant will enable researchers at the newly established Centre for Clinical Research Excellence to work with selected Aboriginal Community Controlled Health Services. Indigenous health service staff will be involved in the research and supported to improve their research skills, ensuring that people who work at grass roots level have the knowledge to contribute to the long term health of their communities.

“HIV and other viral infections ... cause infertility, illness and death in communities, not just around the world, but right here in Australia,” noted the Honourable Minister for Health and Ageing, Nicola Roxon.

Charged with endangering lives

In April, a South Australian man with HIV pleaded not guilty to endangering the lives of eight men by

having unprotected sex with them in incidents that occurred in Adelaide between January 2001 and January 2006. It is alleged he met the men through a gay dating website and had unprotected sex with them after testing positive for HIV. It’s also alleged that when confronted about the possibility that he had infected others with the virus he remarked, “that’s their problem.” In a case widely reported by Australian media, the prosecution has admitted that the case is a difficult one to pursue and that the trial will be a complicated one.

“Since 2006, the criminal law has been invoked as never before to prosecute Australians living with HIV, to punish non-disclosure of HIV status to sexual partners and transmission of HIV through sex,” commented HIV consultant John Godwin. Meanwhile, related cases, similar and dissimilar appear around the world with very different results. In Iowa, where gay marriage was recently legalised, a 34-year-old man was sentenced to 25 years in prison for a one-time non-disclosure to a single complainant, who did *not* test HIV-positive. It was not reported whether a condom was used during the single encounter.

But in Geneva, Switzerland, the Court of quashed an 18-month prison sentence given to a 34-year-old HIV-positive African migrant convicted of HIV exposure by a lower court in December 2008, after accepting expert testimony that the risk of sexual HIV transmission during unprotected sex on successful treatment is 1 in 100,000. Geneva’s deputy public prosecutor, Yves Bertossa, stated: “One shouldn’t convict people for hypothetical risks.” Compare that to Judge Bradley Harris’s sentencing in Iowa: “One thing that makes this case difficult is that you don’t look dangerous; you don’t look

like most of our criminals that sit here. But the risk is still there, just like if you would have shot a gun.”

Give us time to adjust to same-sex law reform

Same-sex law reform and pension changes are long overdue, but time is needed for transition to prevent harm for those most vulnerable, say community advocates.

From July 1 2009, changes to Australian legislation will be enacted recognising gay, lesbian, bisexual and transgender (GLBT) relationships in many (but not all) areas of law. Whilst these changes are welcome, there are real concerns that negative consequences of social security reform will disproportionately impact the community's most vulnerable members, including the elderly, people with a disability and people with living with HIV or other chronic illnesses. All previous major Australian social security reforms have had transitional arrangements.

The Australian Federation and AIDS Organisations (AFAO) and 23 other community health organisations have signed a statement advocating

for provisions including exempting vulnerable community members from being treated as a couple, a delay of implementation until July 2010 to allow for preparation and education, and saving provisions for pensioners.

Near universal human papilloma virus (HPV) in gay Australians

Anal infection with human papilloma virus (HPV) is at near universal levels in gay men, a study conducted in Australia has found, **reported Michael Carter** at *aidsmap.com*.

Significant numbers of men were infected with strains of the virus that carry a high risk of cancerous and pre-cancerous cell changes in the anus. The investigators also found that levels of HPV infection were particularly high in HIV-positive gay men, who were also more likely to be infected with multiple strains of HPV.

Although rare, rates of anal cancer are higher amongst gay men, particularly those with HIV, than in the general population. Researchers in Sydney, Australia, conducted a study involving 127 HIV-positive and 204

HIV-negative gay men recruited from the community. Anal HPV infection was found in 79 percent of men overall. The prevalence was significantly higher in HIV-positive men (94 percent) than HIV-negative men (70 percent).

'Ratting' on teens with condoms

ABC news has reported on the Northern Territory's Minister for Child Protection confirming that state pharmacists are required to report anyone under sixteen who buy condoms.

The Australian Medical Association (AMA) has described the legislation as unworkable because it makes it illegal not to report teenagers under 16 years of age who are sexually active. The AMA warns the laws could increase teenage pregnancies and sexually transmitted infections because young people would be afraid of seeking sexual health advice and contraception.

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The logo for HIV Australia, featuring the words "HIV" and "AUSTRALIA" in a large, bold, sans-serif font. The letters are grey with a slight shadow effect, giving them a three-dimensional appearance. The word "HIV" is positioned above "AUSTRALIA".

Got something to say?

Your views are important to the success of this publication.

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

NEWS FROM THE ASIA PACIFIC

Tying Human Rights to sexual orientation

The Asia Pacific Forum concluded a meeting in May 2009 with a call to “advance human rights in our region on sexual orientation and gender identity.” They recognised a serious problem in the Asia Pacific of “discrimination and violence against people of diverse sexual orientation and gender identity,” including “execution or extra-judicial killing, torture, rape, arbitrary detention, unfair trials and, in the case of women, forced pregnancy and forced marriage,” at the hands of both state and non-state actors.

They vowed to work to implement the *Yogyakarta Principles* – a set of binding international legal standards relating to sexual orientation and gender identity to which all States must comply. It was also agreed that further efforts must be harnessed to encourage their members and national human rights institutions in the region to use their functions and powers – including investigating complaints, reviewing laws and policies, holding national inquiries and public education – to better protect and promote the rights of gay, lesbian, bisexual and transgender people.

Australia converts commercial debts to Indonesia into health programs

AusAID and the Global Fund reported in May 2009 that Australia has offered to write off AUS\$75 million in commercial debt to Indonesia. In return, Jakarta has agreed to invest half that amount in domestic tuberculosis programs that are supported by the Global Fund to

Fight AIDS, tuberculosis and malaria. After Germany, Australia is only the second country to join the Global Fund’s debt-conversion initiative, known as Debt2Health, but will be the first to offer to cancel commercial debt under the program.

Australia’s Parliamentary Secretary for International Development Assistance, Bob McMullan, commented, “I am proud that Australia is joining Debt2Health, which demonstrates the Australian Government’s commitment to finding innovative solutions to the needs of poor families and individuals in developing and emerging economies.” In the midst of the Global Financial Crisis, it is imperative for governments to find innovative financing models for poor countries to continue to respond to HIV and other major health crises.

Taiwan: an example for harm reduction

Reports from the International Harm Reduction Association’s annual meeting, held in Bangkok in April 2009, show Taiwan as a shining example for harm reduction in the region. The meeting gathered more than 900 colleagues and practitioners from over 80 countries to address a context where only two to three percent of injecting drug users (IDUs) are receiving benefits from harm reduction services in the region. At the same time, IDUs currently contribute a substantial 10 percent to the newly transmitted HIV infections.

Taiwan provided some good news though. In 2005, Taiwan recorded its highest number of new reported cases of people infected with HIV – over 3,300 – nearly twice the number

recorded the previous year. The (now former) Minister of Health recognised the effectiveness and the need for harm reduction in Taiwan and set about convincing peers – key government officials with decision-making powers – to adopt a harm reduction approach to HIV amongst IDUs based on human rights. By the end of 2008, new HIV cases had dropped to 1,752 cases, which was an over 50 percent drop in the number of new HIV cases among IDUs during a three year period.

Taiwanese IDUs were not viewed as criminals for their drug habit; they were presented to the public as ‘patients’ in need of help. The public health initiative, launched in 2006, ranged from greater screening and monitoring of drug users living with HIV, a needle exchange programme, and a drug replacement therapy with methadone.

CDC-Taiwan officials have also reflected on the financial savings incurred through their harm reduction program, representing approximate savings of USD\$150 million (2005–2008). Pascal Tanguay of the Asian Harm Reduction Network commented, “it should be noted that Taiwan’s harm reduction program is currently being implemented with national resources and has little or no dependence on external donors. As the Commission on AIDS in Asia noted, complacency in the region is widespread but the example of the Taiwanese efforts to address drug use through an evidence-based response demonstrates that some Asian governments can, and are willing, to do what is necessary to protect their citizens.”



INTERNATIONAL NEWS

Men who have sex with men (MSM) and transgender issues: reversing neglect?

In May 2009, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United Nations Development Programme (UNDP) launched a new UNAIDS Action Framework on Universal Access for men who have sex with men (MSM) and for transgender people. The Framework sets out how UNAIDS will facilitate and support universal access to HIV prevention, treatment, care and support for men who have sex with men and transgender people. The approach taken in the Framework aims to reduce the incidence of HIV everywhere, while protecting the health and rights of not only men who have sex with men and transgender people, but also their female sexual partners and the rest of the population.

This important document and policy direction is necessary, as multilateral agencies, NGOs and governments have all been insufficient in addressing this population:

“... collective responses to HIV in the men who have sex with men and transgender populations are failing. The problem has either been ignored – with insufficient data and analysis – or commitment and resources allocated to HIV programming in these populations fall far short of what is required.”

Furthermore:

“the failure to respond effectively has allowed HIV rates to reach crisis levels in many communities of men who have sex with men and transgender people,”

said Michel Sidibé, Executive Director of UNAIDS. “Efforts to reverse this crisis must be grounded in human rights and underpinned by the decriminalisation of homosexuality,” he added.

Universal testing + universal treatment = big impact

What would be the effects of universal testing for HIV and immediate ARV treatment for those found to be positive? A modelling study published early this year in *The Lancet* proposes a huge impact. Reuben Granich and his fellow co-authors from the World Health Organization (WHO) note that roughly 3 million people worldwide were receiving antiretroviral therapy (ART) at the end of 2007, but an estimated 6.7 million were still in need of treatment and a further 2.7 million became infected with HIV during the same period. While prevention efforts can reduce HIV incidence, eliminating HIV requires risk behaviours or viral transmissibility to be reduced substantially: easy in models, not in practice.

So the authors investigated a theoretical strategy of universal voluntary HIV testing (at least 90 percent of the population) and immediate treatment with ART (regardless of CD4 level), and then examined the conditions under which the HIV epidemic could be driven towards elimination. They found that the strategy could greatly accelerate the transition from the present endemic phase, in which most adults living with HIV are not receiving ART, to an elimination phase, in which most are on ART, within five years. It could reduce HIV incidence and mortality to less than one case per 1000 people per year by 2016, and reduce the prevalence of HIV to less than one percent within 50 years. Although initially more expensive than present practice, the authors argued that such a scaled up approach might actually lead to elimination of HIV and would save money by 2050 as there would be less people to treat.

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Top four needs of people with HIV in the UK all related to mental health

Anxiety and depression, self-esteem, sleep and sex are the areas of life that pose problems to the greatest number of people living with HIV in the UK, according to a new study published by Sigma Research. They note that these problems relate to the intimate details of personal experience and quality of life,

rather than to practical and physical problems, reported Roger Pebody at *aidsmap.com*. However, in many instances, people experiencing problems had not received any help or support during the past year. When people did receive help with the top four issues, it was frequently from clinical services, but informal support from friends and family was also highly valued.

A total of 1,777 self-completed questionnaires were completed by

adults living with HIV in the UK. The sample was disproportionately male, gay or bisexual, and over 45 years of age. But the report addressed this bias by providing analyses of the needs of specific sub-groups such as women, young people, black Africans, people with immigration problems, and people who are recently diagnosed. Many respondents described the cause of their anxiety and depressions as explicitly related to living with HIV. Moreover, among the most common causes cited for problems with self-esteem and self-confidence were worries about the future, changes in appearance or body and worries about disclosing HIV status. The most frequent problem related to sex was having too little or no sex and this was often linked to poor self-image.

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Next Steps

A new booklet for people recently diagnosed with HIV

Information on a range of issues including treatments, safe sex, looking after your health and the stages of adapting after diagnosis.

Includes real-life stories from people who have been diagnosed with HIV.

Next Steps
NOW AVAILABLE FROM YOUR LOCAL AIDS COUNCIL OR PEOPLE LIVING WITH HIV/AIDS ORGANISATION

AFRO
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From partnerships to 'post AIDS': Is this marriage still worth it?

By Ian Rankin

'Australia is facing the possibility of a serious epidemic of human immunodeficiency virus (HIV) infection. This could cause immense suffering and have major economic and social consequences.'

It is easy to forget that we didn't know what to do about AIDS when it first arrived in Australia. The creation of the much lauded 'partnership approach' to HIV was a result of not having the answers, and a recognition that traditional responses to infectious diseases wouldn't work. The capacity and performance of this partnership approach has changed over time. Why did it arise, where is it now and what foreseeable challenges will it need to confront?

The scale of the policy challenge provided by AIDS was described in the first national policy discussion paper *AIDS: A Time to Care, A Time to Act* as:

*'Australia is facing the possibility of a serious epidemic of human immunodeficiency virus (HIV) infection. This could cause immense suffering and have major economic and social consequences.'*¹

In response to this challenge, novel policy arrangements were established and flourished. The engagement of

people directly affected was an unusual step, taken because it was arguably one of the few viable policy options available. Stephen Duckett notes that:

*'The response (to AIDS) could thus have been one of blaming victims, and further stigmatising those affected. Prior to the advent of AIDS, the engagement of community was not a characteristic of public health policy.'*²

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In terms of policy options, ‘partnerships’ are as old as governments. The partnership that was established in response to AIDS in Australia was unusual due to the inclusion of non-traditional partners in a health response. Working in cooperation formed the basis of the community, political, medical and research efforts to respond to AIDS in Australia. The term ‘partnership’ did not appear in Strategy documents until the Second National HIV/AIDS Strategy³ and wasn’t used extensively until the endorsement of the Feacham Review which defines:

*[t]he concept of partnership involves a commitment from all parties to work together as equals to solve the problems created by HIV/AIDS’.*⁴

The access, funding and authority given to organisations of gay men, sex workers and injecting drug users provoked considerable debate and conflict. Neal Blewett, the Health Minister at the time, recalls:

‘The marginal nature of the groups affected may also have influenced state attitudes. It was, I suspect, only partly a joke when a state ministerial colleague commented to me, “Look, mate, there are no votes in buggers, druggies and

*prozzies!” To further complicate matters for some state health ministers, in three of the states the chief mode for the spread of the disease – male-to-male sex – was an illegal activity’.*⁵

These were novel groups to include and as with many new relationships the building of trust took time. As Paul Sendziuk argued:

*‘Australia’s approach to AIDS prevention became recognised as one of the most innovative and successful in the world because politicians and, I think one can argue, doctors and the public, came to consider gay men, prostitutes and injecting drug users as they and their supporters imagined themselves; as trustworthy’.*⁶

This trust arose from results. The HIV/AIDS community declared itself committed to the fight against AIDS, it provided education and support programs. It raised money as well as practical and political support from within its constituencies. The community provided access to the most valuable of policy resources: the wisdom and insight of the people most at risk of infection. Over time, this response was shown to reduce infection rates and assist in the care of people

living with HIV. The delivery of these results enhanced and consolidated the community sector’s role as equals in the response to the epidemic.

The strategies and partnership arrangements worked well in terms of decreasing levels of infection up until the mid to late 1990’s, but it did so in the context of increasing numbers of deaths from AIDS. Annual recorded diagnosis of HIV fell steadily from 1703 in 1988⁷ to 718 in 1999⁸. Deaths from AIDS rose from 223 in 1988 to a peak of 738 in 1994 and then dropped rapidly to 141 in 1999, a decline that thankfully continues (67 in 2008). The epidemic experienced was considerably smaller than the early projections of potential infections. While these were continually revised as new data became available, it is important to note that these early figures provided considerable impetus for the policy experimentation in the early response to AIDS and the level of resources committed.

The policy problem of AIDS changed from 1996 onwards with the advent and implementation of successful HIV antiviral therapies. The number of people living with HIV infection was estimated at 11,080 in 1997⁹ and a decade later the estimated number of people living with HIV in Australia was 16,692¹⁰. This is good news and not-so-good news. Good news because it reflects the dramatic drop in the death rate, but bad news (in policy terms) because it also reflects a major upswing in the HIV diagnosis rate, which reached 1,051 in 2007.¹¹ The reduction in deaths from AIDS has occurred concurrently with an increasing trend of new infections. There are various factors at play, but it is feasible to argue that the reduction of a perceived threat from HIV infection at the personal level,

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combined with an increasing population of people capable of infecting others, has started a trend in infections that is potentially exponential.

The relative absence of death from the policy landscape has diminished the level of public support for HIV prevention. This can be discerned from a significant decline in the level of media coverage of HIV during the early 2000s, decline in the membership of various community organisations and commentary in gay media about being 'over AIDS': wanting to move beyond association with a stigmatised medical condition. The welcome relief drug therapies have delivered has also reduced the level of political and community engagement among the population most directly affected at a time when the numbers of HIV-positive Australians are growing. AIDS is still a serious challenge, but it certainly does not attract the same passion, fervour and interest of a decade ago.

During the last two decades there have been fundamental changes in the nature and operation of the community most affected by and at risk of HIV, the gay community. Growth in technology options for communication has reduced the reliance on particular places, such as bars, to experience 'gay life'. Also the nature of 'gay' has been transformed through various cultural, legal and social advances that have reduced the social marginalisation and institutional hostility to gay people.

While these are welcome advances, they also bring consequences for a response to HIV that was fashioned in a different cultural setting. This diffusion of gay life has made reaching gay men in Australia a more complex task than in the 1980s. Combined with the 'over AIDS' sentiment, this

has meant a reduction in the level of contribution from the gay community to the contemporary response to HIV.

Are we now 'post-AIDS' in Australia? Compared to the epidemic (real and forecast) that informed the creation of the policy framework and strategies in the 1980s, yes, undoubtedly. There is now an expanding epidemic of a less lethal virus with different social, economic and cultural consequences. There is a reduction in capacity to get people and communities involved and investing in the response to HIV. Positive developments, such as extended life spans, reduced social stigma, and a widespread (if not universal) adoption of safer sexual practice, have changed the policy environment. Will the partnership response remain relevant and useful? If so, how?

To assess the viability of the partnership approach to HIV/AIDS we need to confront some difficult questions. Will partnership deliver the results we want? If the objectives remain to reduce transmission and increase the quality of life for people with HIV, how might this come about? Will the described partnership of equals – containing government

leadership, community engagement, medical care and evidence-based research – provide a reasonable chance of delivering these policy objectives? What are the costs of doing more, doing less or doing nothing?

Doing more will be cost-effective in terms of the health budget if it delivers results. Successful prevention is far cheaper than life-long treatment. The avoided morbidity, combined with effective quality of life measures for people with HIV also have wider economic and social benefits beyond the bottom line of health expenditure. In seeking to secure additional resources, the current response to HIV will have to compete against other causes of mortality and morbidity for funding. For example, only the most pessimistic forecast would suggest 20,000 deaths from AIDS over the next two decades, and there are more deaths each year caused by smoking and related diseases.

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A Commitment to Revitalisation: Introducing Michael Kidd, the new Chair of the Commonwealth's Ministerial Advisory Committee

By Abigail Groves

My background is as a medical practitioner. I've been working in general practice with people living with HIV for about twenty years ... and I've also been involved in advocacy work.

Earlier this year, Health Minister Nicola Roxon announced the formation of a new Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections (MACBBVS). The Committee provides advice to the Minister about how to respond to HIV, viral hepatitis and STIs. The Chair of the Committee is Professor Michael Kidd, a clinician who specialises in HIV. He spoke to Abigail Groves from *HIV Australia* about the new Committee and directions in the government's policy in relation to HIV.

Abigail Groves: I understand this is a ministerial appointment. Can you tell us about your background and how you came to this appointment?

Professor Michael Kidd: Clearly, the Minister makes the appointment, exactly what process the Minister went through, I don't know. My background is as a medical practitioner. I've been working in general practice with people

living with HIV for about twenty years. I've been involved in doing research around aspects of HIV, involved in a lot of health professional education around HIV, and I've also been involved in advocacy work.

It's certainly a very strong background in HIV.

It's a long background.

How did you get involved in HIV?

It was pretty simple. I did my specialist training in general practice in the mid 80s, and then when I finished my training I looked around to decide what sort of general practice work I wanted to do for my clinical work. As a gay man I could see HIV was affecting people I loved and cared about. It was affecting people that I knew; it was affecting our community, so it was an opportunity to make a difference. There was then, as there is now, a need for health professionals who were willing to work in HIV medicine, to work with people with HIV.

What was it like to be a GP working in HIV in the early years of the epidemic? I imagine it must have been quite a scary time.

I don't know about scary, but it was a very challenging time because prior to the introduction of successful triple therapy, which occurred in 1995–96, the therapies were not very effective. Large numbers of people were dying in Australia from AIDS-related conditions, so it was a very challenging area.

It was actually wonderful working in a multidisciplinary clinic, like the clinics that had been set up by the Victorian AIDS Council and the Gay Men's Health Centre (VAC/GMHC), because I was working side-by-side with so many dedicated professionals. We had a great team of support staff who were very caring towards people who were coming into the practice. The carers and volunteers were extraordinary – people who were providing extraordinary levels of care to people who were dying, but dying with dignity, often in their own homes. Of course, it was very sad as well.

And then we went through this remarkable period in 1995–96 where triple therapy became available and, all

of a sudden, people who thought they were inevitably going to die over the next few months – their health started to improve. It was the most remarkable time in my professional career, where suddenly modern medicine had the ability to literally save lives in such numbers so quickly. It's probably comparable to when antibiotics were first introduced around the world in the 1930s and 1940s.

It was a pretty remarkable time, but of course the clinical challenges didn't stop, they just became different. The new treatments brought with them very significant side effects. A lot of people who had their health improve still had residual health problems related to the impact that HIV and the associated diseases from before the treatments become available.

A lot of people had serious mental health challenges. There was a lot of sadness, a lot of depression, a lot of grief, like where one partner had died prior to 1995–96 and the other partner thought they were going to die and then didn't. A lot of very complex issues. And, of course, they continue today.

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What do you see as the challenges today, both in critical terms and for the national response to HIV as a whole?

Here in Australia we've had a very effective response to HIV since it first appeared. Much of the secret of that response has been the preparedness of government in Australia to engage in partnership with affected communities; with clinicians, researchers and many other people in the wider community, all working together to develop a national response to HIV, ensuring that we have strong and explicit education programs targeted to groups of people who are at increased risk of HIV or have been affected by HIV. Strong programs to provide care to people with HIV.

When I was invited by Health Minister Nicola Roxon to Chair this new Ministerial Advisory Committee, I had no hesitation in saying yes. The Minister has made it very clear to the committee that she's committed

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to the national strategies; committed to working with the states and territories on the implementation of the national strategies – to make sure that the components of the strategies can be rolled out across the country; and committed to revitalising the partnership response, which has been so successful to date.

The Minister has made a strong commitment to do what she can to bring about a turnaround in the rising number of new HIV infections in Australia. We've seen quite significant increases in different parts of the country over the last decade. Now we have the Australian government's new national safe sex campaign being launched in May. So things are moving ahead and they're the sort of things that we're doing with the National Committee.

I know that the role of the Chair of the committee, which has had various names and incarnations over the years, has waxed and waned in terms of its public profile. I was

wondering what your thoughts are around the public profile of Chair of the committee?

When Australia first established a committee focusing on HIV, it was a national council. It had a very strong public profile and a lot of media attention, and it was very involved in actively rolling out programs to increase public awareness and increase support for people with HIV. Now it is a Ministerial Advisory Committee, so it provides advice to the Minister on the national response to HIV, to hepatitis B, hepatitis C, sexually transmissible infections and issues affecting Indigenous sexual health. It's a very broad responsibility to ensure that the Minister is kept up to date on key issues as they're arising, to develop the national strategies and to present those to the Minister as our recommendation on what the Australian Government should be doing in each of these areas. The committee will continually monitor what's happening with the national strategies and their rollout.

However, the Minister has also said that she wants the committee to be visible, and to that end I've been travelling to each State and Territory, meeting with researchers and clinicians and service providers involved in treatment and care. I've been meeting with national representative and advocacy and education organisations, to listen to people's experience about what's happening with HIV and the other conditions in their part of the country and to bring that all together. And, at the same time, I am also sharing with people exactly what it is that we plan to be doing over the coming three years.

We have an extraordinary range of talent on the committee itself. The 17 committee members cover a breadth of expertise, from advocacy organisations, from people affected by the conditions we're looking at, people with expertise in indigenous health and education, expertise in anti-discrimination practices and expertise in clinical care and research. It's a great group of people.

There was some criticism of the government's leadership in the response in recent years, particularly to HIV, but also to hepatitis and Indigenous sexual health. How do you see the Government's role and the department's role in terms of leadership?

Well, there's been a review of the previous set of national strategies, which ran until the end of last year. There are some very important themes which have emerged from the consultation process held with many organisations involved in HIV about what worked well with previous

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Leading questions: weighing up the leadership of the community HIV response in Australia

By Brent Allan

Many of the successes of the response to HIV in Australia have come about through inspirational and courageous leadership in the community response

Many of the successes of the response to HIV in Australia have come about through inspirational and courageous leadership in the community response, research, clinical care or in the political arena and indeed through the partnerships between these parties.¹

Understanding the qualities of leadership, examining the behaviours, styles and aptitudes of effective leaders and placing these into the context of the HIV response in Australia allows the current leadership to consider ways to sustain an effective leadership response into the future. It also allows us to imagine what actions can be taken today to support new leaders, while continuing to capitalise upon the leadership capacities of the previous and current leadership.

This article arose from a research project which aimed to better understand the unique place of

leadership in the HIV community response in Australia. Though not an exhaustive study of current or past leaders, this project did seek to gather personal perspectives on the performance of leadership from those who have experienced the Australian community response to HIV.

Over one month, 16 people were interviewed – half currently held leadership positions in the field of HIV in Australia. They worked in a variety of roles, in governance, management, research and project work. The other

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half of the sample had previously held such positions but had moved on.

The interviews consisted of a series of questions which encouraged the interviewees to reflect upon the capacities and limitations of the leadership in the HIV community response in Australia, both in its current state and from its history over the past two decades. The interviewees were also encouraged to consider the contextual environment in the future and to describe what the leadership response to HIV in Australia should, or could, be like. Finally, the interviewees were asked to describe the qualities of leadership that they have admired in those that they have seen as effective leaders in the response, including the option to recommend people with whom the interviewer could speak to regarding the notions of leadership in the community response to HIV.

Defining leadership

There was a long list of qualities and behaviours that people saw as emblematic of an effective leader, many of which the current research suggests are admired broadly in the community. These include attributes such as honesty, the capacity to inspire, self-confidence and adaptability.²

However, there was also an interesting set of qualities or capacities that

interviewees identified which can best be described as “sense-making” (a term coined by Karl Weick, 1995³.) The act of sense-making is discovering the new terrain as you are inventing it. Many interviewees spoke at length of leaders who contemporised issues as they arose and described leaders who displayed an “accessible informality”, an “ability to merge facts with lived realities”, and “insightful creativeness”. They spoke of leaders who could identify what works in context and leaders who were able to “push the boundaries of new thinking and new ideas”. These were leaders who were able to interpret the meaning of behaviours – to “think through the issues” and place these into a myriad of social contexts and describe a variety of potential outcomes.

The second most nominated cluster of qualities that people said they admired were those that are best described as “relating”. The core capabilities of “relating” centre on a leaders’ ability to engage in inquiry, advocacy and connecting. Inquiry and advocacy in relation to the theory of leadership are terms coined in the pioneering work of Chris Argyris and Don Schon (1996⁴), as well as Peter Senge (1990⁵). In the context of the community response to HIV, these concepts were often referred to in relation to the strength and breadth of inquiry by leaders in the fields of research and service delivery

(clinical, social and community-based) and the enormous degree to which these programs, services and studies were community initiated, supported and endorsed.

The notion of being a strong and effective advocate was a quality admired and respected by many of the interviewees. Early advocates/activists in the community response to HIV in Australia were often referred to with such terms as “having guts”, “being driven”, “knew what they wanted and went for it” and “fearless”. These leaders were often credited with extraordinary lobbying abilities; with having a depth of knowledge of communities and their issues; and were prepared to name issues, especially those which were unpopular with decision makers, peers, or indeed the community itself.

The third aspect of relating – “connecting” – was possibly the most often referred to aspect of an effective leader. These leaders were described as having the ability to build collaborative partnerships with others and to create coalitions for change. These were leaders who “brought people along”, “inspired others to contribute”, and “gave people time and space to develop.” All interviewees were able to describe leaders who in one form or another, brought about change by bringing people together. As one person qualified, “they had a remarkable ability to give voice in a compelling way to an enormous array of different audiences.”

At the end of the interview, people were asked to consider who they would recommend to be contacted in relation to the notion of leadership in the community HIV response. Over 60 different people were identified as leaders of significant note and 24 individuals were identified multiple times by the 16 interviewees.⁶ Although this was an investigation into the leadership of the community response to HIV, in some cases certain people were identified who “crossed

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boundaries.” These people were referred to as both as a researcher, an academic, a clinician, a politician, as well as a member of the community and a leader in the community response to HIV.

The strengths of the response

Many people spoke of the extraordinary passion and commitment that has been a hallmark of the response from leaders to HIV in Australia. This passion and commitment arose from “talented amateurs” who had perhaps crafted their leadership skills in other forums and were recruited from a common background to deal with a then-relatively unknown and highly stigmatised disease. It was in this context that brave leaders came forward – some of whom did so in response to the real and immediate threat to their own lives, those of their friends and their loved ones. Some of these individuals are still working in the sector in 2009, others have moved on to other fields and several, of course, have died.

Interviewees spoke of leaders who excelled in advocacy and lobbying, leaders who were able to mobilise a community response in partnership with government – despite significant apprehension from the wider community, often fuelled by misinformation and stigma. These leaders shared a common belief in social justice, human rights, community activism and community empowerment. Although these individual leaders may have come from different backgrounds, there continues to be a shared sense of these ideals and ethics which guided the response.

Certainly, the notion of a community response (as opposed to merely an organisational response) has meant that the leadership guiding the response has been highly attuned to the values and voices of the community. It has also meant that truly remarkable leaders have worked beyond singular

notions of community, bringing together disparate communities and exemplifying “an ability to speak across substantial differences towards common goals,” and an “unwavering fortitude to reconciling the desires of many populations.” An ability to mark and measure these differences and the challenge to bring them together have meant that leaders have had to guide and lead change as different issues have manifested. This includes not only issues from within the sector itself, but also from within the communities that make up the sector.

Perhaps the most surprising theme emerging from the interviews was the personal nature of the leadership response – both in its totality and from specific individuals. Many people spoke of either wanting or watching leaders “making a difference”, of bringing people together in a period of crisis and trying to make sense both for themselves and for their communities. This personal connection to the issue, this motivation, established leaders who were profoundly bonded to the issues, the responses and the outcomes. This personal commitment to the response was articulated as both a strength and a liability. Although it galvanised people inside a community, “embedding a response within a community”, it was also thought to “engender bias too heavily influenced

by personal experience and not by evidence or research”.

As the interviews continued, it was the opinion of many that the HIV community response in Australia has been populated with articulate, committed, intelligent and insightful leaders who have striven to find solutions to complex problems with affected communities.

The challenges faced

With leaders displaying such passion and personal commitment through a period of crisis, there was concern amongst interviewees about whether this passion and commitment can be maintained and whether the leadership today is both considering and preparing new leadership responses for tomorrow.

There was a sense that the community response to HIV was typically one of “constant recycling of the same people into different positions”. There was much discussion about the consequences of this lack of renewal, and concerns that one consequence would be the diminishing relevance of the HIV sector. It was felt that this pattern, in which a small number of

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Positive Leadership: its evolution and continuing importance¹

By Sally Cameron

Positive people played a vital role in Australia's HIV partnership from the start, although that role has not always been clearly defined. Australia's urban gay populations mobilised around HIV/AIDS with impressive force.

The first public declaration that personal experience should shape responses to AIDS was recorded in Denver in 1983.² Whether or not any similar unrecorded assertions occurred earlier, that date is important for two reasons. Firstly, it came very soon after AIDS was identified in the US (and in Australia) in 1982. Despite only very few people having been diagnosed with AIDS, those people (not yet called positive people) demanded the right to own their experience and the public policy response to it. Secondly, 25 years is a long time, yet in many parts of the world, positive people continue to be locked out of all but the most basic level of response to HIV: their 'participation' being, at best, access to basic medication and treatments.

Australia's early response to HIV/AIDS is widely recognised as being of international best practice standard. Following the identification of AIDS in Australia, federal and state governments responded with surprising acuity. They refused to bow to public backlash and insisted on controversial public health strategies such as condom vending machines, needle and syringe disposal bins, needle and syringe exchange programs and, most importantly, publicly talking about the risk factors for HIV transmission. Simultaneously, communities mobilised and community-based HIV

organisations (such as AIDS Councils and other support organisations) were established. Communication between community and government was strong, and the 'partnership approach' to HIV public policy was born.

Positive people played a vital role in Australia's HIV partnership from the start, although that role has not always been clearly defined. Australia's urban gay populations mobilised around HIV/AIDS with impressive force. They were smart, strategic and effective: lobbying government for funding and an appropriate public policy response; building effective HIV

service organisations, some of which rapidly grew in size; and developing wide-reaching understanding among gay communities of risk factors and the importance of safe sex and mutual responsibility. By 1983 (one year after Australia's first recorded case of AIDS), AIDS Councils were operating in South Australia, Victoria and Western Australia. By 1985, they were also in NSW, Queensland, Tasmania and the ACT. Positive people were present, but where were they?

In 1987, three brave individuals publicly identified themselves as HIV-positive during Australia's Second National AIDS Conference. In 1988, the Third National AIDS Conference saw a mass 'coming out' of people living with HIV/AIDS (PLWHA). Positive people had 'arrived'. That year PLWHA Victoria and Positive Women (Victoria) were founded. The following year the PLWHA NSW Coalition and the National PLWA Coalition (now NAPWA) were formed. Positive people had organised to establish independent organisations, to better facilitate discussion and represent the experience and needs of people living with HIV/AIDS.

The Greater Involvement of People Living with HIV and AIDS (GIPA)

Lagging somewhat, the international community finally organised itself to publicly declare the principle that positive people should be involved in developing responses to HIV/AIDS at the Paris AIDS Summit in 1994. The GIPA Principle (Greater Involvement of People Living with HIV and AIDS) was formalised when 42 countries agreed to 'support a greater involvement of people living with HIV at all ... levels ... and to ... stimulate the creation of supportive political, legal and social environments'.³ GIPA aims to realise the rights and responsibilities

of people living with HIV, including their right to self-determination and to participate in decision-making processes that affect their lives.

Six years later, the Consultation on the Greater Involvement of People Living with or Affected by HIV/AIDS was held in Nairobi to gain insight into challenges and opportunities related to the GIPA initiative. That consultation found that while GIPA was a brilliant concept on paper, much needed to be done to make it a reality. The definition of GIPA was also expanded to include those most directly affected by HIV.

The report argued that:

*"It is critical that we do not lose sight of the importance of GIPA – which is not to promote exclusivity of living with HIV – but rather to increase the effectiveness of policy and programming by including those living with the virus in their lives – with or without being infected – at all decision making levels."*⁴

The overall consensus of the meeting was to expand GIPA from including only those with HIV, to also include those most affected by HIV. In 2006,

GIPA was endorsed by 192 Member states at the High Level Meeting on AIDS. GIPA is now implemented – to varying degrees and with varying levels of success – worldwide.

Why involve HIV-positive people in Australia's AIDS response?

People living with HIV know what it means to have HIV. They have direct experience of the factors that make individuals and communities vulnerable to HIV infection. They have lived HIV-related illnesses and developed strategies for managing them. They have experienced discrimination, isolation and stigma. They understand issues around disclosure. They struggle with treatments. The list goes on.

By 2008, there is substantial evidence that given their intimate insight, positive people's involvement in program and policy development also leads to better programs and services.

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Although GIPA doesn't require disclosure, those that are openly HIV positive and engaged in constructive change give HIV a public 'face', breaking down community fear and prejudice. Positive involvement can also deliver rewards for individuals involved. It can draw participants into a community response (decreasing isolation), improves access to treatments (through increased knowledge and access to health services), and increase self-esteem through their achievements.

Although measuring the involvement of positive people is not a simple or exact science, we know it is not simply about 'counting heads.' HIV negative service providers delivering HIV services to HIV positive people does not satisfy GIPA's demands. Neither is it about tokenistic participation. GIPA describes meaningful involvement. The results of GIPA on the ground have been so varied, and in fact lacking in some regions, that some have called for use of the term 'MIPA': the Meaningful Involvement of PLHIV and Affected Communities, as a means to emphasise that GIPA's intention was always to communicate positive people are active and equal agents of change.⁵ For now, however, GIPA remains the favoured acronym; 'the meaningful involvement of PLHIV and affected communities' is its meaning.

Positive-run agencies and networks are central to the achievement of GIPA. Unfortunately, many positive organisations face significant challenges. Internationally, meetings of positive people have identified numerous constraints. These include: weak management, low skill levels, funding constraints, difficulties in representing the diversity of people living with HIV, a lack of documentation of histories of self-empowerment, and a lack of evaluation of successes and failures.⁶ Some of these

factors are unusual in the Australian context, while others are apparent. In Australia too, individuals' capacity to contribute may be restricted by their experience of prejudice, including homophobia and gender inequality, while others are preoccupied by their basic daily lives, including managing illness, treatments, financial insecurity and isolation.

In order to maximise GIPA's potential, positive leadership is vital. The *National HIV/AIDS Strategy 2005–2008* recognises that 'people living with HIV must be placed at the centre of the national response and be supported in providing a leadership role that guides and supports the national response.' The challenge is to make that commitment a reality.

What does Positive Leadership look like?

AIDS activism has become an important social and political component of the lives of many people living with HIV⁷, and positive leaders are agents of social change. Ostensibly, that leadership is about advocacy: advocating for the needs of positive people in a community, in a region, or throughout Australia. Leadership can take a variety of forms but arguably, it is at its most impressive and effective when it arises from grassroots movements and community-building expressed through consensus.⁸ Positive leadership cannot be about personal agendas or charismatic personalities, but must be about working with communities to mobilise and lead civic action.⁹ The positive-led response to HIV/AIDS in Australia grew from a grassroots movement driven by the spontaneous focus and energy of individuals and, later, communities of positive people, rather than a movement orchestrated by traditional power structures. It is grassroots: not 'astroturfing'.¹⁰

'Advocacy is one of the proudest, most productive legacies of HIV communities because of its record of transforming attitudes'¹¹, so the responsibility is not to be taken lightly. The task of adequately articulating a community perspective is formidable. HIV-positive people are diverse, as are their communities. They may share experiences associated with having HIV, but their experiences also vastly differ, informed as they are by their experiences of their gender, sexuality, socio-economic status, ethnic background, occupation, geographic location, educational background, parental status, political allegiances, religious beliefs, as well as their general health, and many more factors besides.

The 2008 *Annual Surveillance Report on HIV*¹² found that by the end of 2007, there had been 27,331 diagnoses of HIV infection and 10,230 diagnoses of AIDS in Australia¹³. There are now almost 17,000 positive people living in Australia and the further one drills down into HIV/AIDS data, the more diverse and multi-faceted the picture of the positive community becomes. When the complexity of individuals' lives (and at this point that means the diversity of experience of some 17,000 positive people's lives) is considered, delivering 'positive leadership' becomes a significant task, particularly if that leadership is to be representative.

Affected communities, needs and issues are constantly changing

The impact of HIV and the corresponding priorities of positive people have continued to change throughout the history of the HIV pandemic. For some time, there has been a sense that HIV is no longer a crisis and as a result, many people have disengaged. The cracks are beginning

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Confidence

HIV-positive capacity building: reclaiming our confidence

By James Watson

As many of us understand, HIV can place enormous strain on the mental health of even the most physically healthy PLHIV. It can put dreams out of reach and damage one's ability to formulate future goals.

The "capacity building process" is an essential part of Community-Based Research (CBR)' and can have a profound impact on the well-being and life course of people living with HIV and AIDS (PLHIVs). 'Capacity building' is an approach to personal/professional development that builds independence. One goal of capacity building is to empower people to address their own challenges, particularly those that arise from social inequities and stigma.

However, questions remain about accountability, sustainability and the power dynamics involved in the CBR capacity building process. There is societal value in our lived experiences as PLHIVs. By sharing some of my story I hope to illustrate a few of the joys, pitfalls and limitations involved in CBR capacity building; by doing so I hope to initiate a discussion on the development of best practices for this vital component of CBR.

As many of us understand, HIV can place enormous strain on the mental health of even the most physically healthy PLHIV. It can put dreams out of reach and damage one's ability to formulate future goals. In my case, I became lost and damaged within the very support program that was supposed to help. I was adrift in a provincial disability support program

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in Ontario, Canada, surrounded by endless bureaucracy. The way home to the safety of 'real world' careers and paid vacations seemed fraught with insurmountable obstacles. I had almost given up hope for a job, let alone a career. I was a specialist at leaping from one cash-in-hand job to the next. This enabled me to live with a modicum of dignity, despite being marginalised as a social pariah for attempting to survive.

As one year faded into the next, my self-confidence eroded and I found myself isolated and depressed. I was embarrassed by my situation and bought into the stigma associated with disability, poverty and social housing. I felt incapable of participating in everyday life. These feelings were exacerbated by my confusion of being physically healthy when I was feeling so miserable. The local AIDS service organisations meant well, but at the time seemed incapable of helping a healthy PLHIV reintegrate into the working world. Prevention, outreach and (at times) oversimplified case management took precedence. I felt

that none of the organisations were capable of offering guidance suitable to my situation.

With nowhere to turn, I turned inward, resentful and angry towards myself and others. I instinctively knew what the problem was; I knew that feelings of inadequacy combined with a lack of ability to control my environment where the reasons why I was miserable, but could find no solution. I needed purpose, direction and meaningful achievement.

I was close to giving up hope when the seemingly impossible occurred. I heard of a job opportunity where an HIV-positive diagnosis was a mandatory condition of employment. Distrusting but desperate, I made cursory inquiries into this possible good fortune. The listing was for a position as a Peer Research Assistant (PRA) for a research study entitled "Positive Spaces Healthy places" (PSHP). I was unsure what was involved but couldn't pass up the opportunity to refocus my knowledge of this disease into something positive.

PSHP was the first longitudinal CBR initiative in Canada to examine the relationship between housing status and stability on the physical and mental health of PLHIVs.² The job description said that "no experience was necessary" *except* the experience of (1) living with HIV and (2) a desire to make a difference in the lives of my peers. As I researched CBR and its holistic approach, an awakening of sorts took place. I no longer felt alone in my thinking that there is more to a person's health than clinical data (with its fearful counting of T cells and viral loads). I recognised the *personal* in CBR and discovered that community ownership and actionable information that makes it possible. The opportunity to be part of this field, where social factors were recognised as determinants of one's health, was one I couldn't let pass by.

After the interview, where my sincerity heavily outweighed my work experience, I managed to secure the job. Thankfully, CBR is a field where lived experience and a desire to build your capacity are highly regarded. This form of research strives to evaluate the social determinants that affect the lives of PLHIVs, while building confidence and skills from within the project itself. This capacity building component is essential and needs to be built-in to any quality CBR project. The goal of the research process and resulting data is to make an impact that is relevant and useful to community organisations, researchers, policy makers and PLHIVs. The impact on my life began the moment we started training as Peer Research Assistants.

I entered the first day of training with six other PLHIVs from across

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the province with eyes open and knees shaking. It was an education I embraced and soon became an ardent supporter of CBR principles. I came to understand that as PRAs, we were central to the project's success. The common experience of living with HIV, regardless of race, ethnicity, gender, culture or any other social construct was a shared life experience of profound importance. A cornerstone of PSHP is PLHIVs interviewing PLHIVs, in an environment of safety and understanding. This key component is not only deeply ethical, but the best way to illicit honest responses. It had been a long time since I was central to work of substance; I could feel my self-confidence returning.

However, it was not all sunshine, rainbows and hugs for all. I was unprepared for some of the power dynamics and politics of researchers of various backgrounds. However, at the end of the day, CBR is kept honest by the PLHIVs embedded in its mission and methods. We were the front line workers in this initiative, responsible for the screening, interviewing and administration of the participants, and were promised future involvement in the analysis and presentation of the results. Our input as PLHIVs carried weight, and was paramount to the projects' integrity. When we raised concerns we were listened to with respect as equal partners. After years of having little influence in society, this egalitarian approach to decision-making was exhilarating.

In hindsight, I may have been somewhat naive to believe that such democratic processes could endure beyond the level of the CBR proletariat.

It seems to me now that if capacity building is to prepare you for your future, protecting you from *all* division and disagreement might hinder rather than help your progression.

It was through the capacity building process that I found a new direction and purpose in my life. Surprisingly, the participant interviews themselves contributed greatly to my personal rehabilitation. Hearing these diverse stories of struggle and survival was difficult, but a profoundly cathartic experience. It was an honour to bear witness to these complex personal tales, and a privilege to be placed in a position of such confidence and trust. At the same time, it is not easy and sometimes exhausting, when parts of your own story are reflected back to you with regularity. This was why, as part of our training as PRAs, we focused on self-care and took the time to debrief as a team. We gained the capacity to keep an appropriate level of distance from participant experiences, in order to prevent losing ourselves in the fog of personal tragedy.

Hearing these diverse stories of struggle and survival was difficult, but a profoundly cathartic experience. It was an honour to bear witness to these complex personal tales, and a privilege to be placed in a position of such confidence and trust.

As the interviews drew to a close the capacity building continued. We were offered opportunities to attend workshops and to present results at research conferences and forums. We added our voices to journal articles, and some were hired to participate as research assistants in other projects. The successes of the study ultimately led to its extension and the continuation of our involvement in the project.

“Capacity building” had a positive effect on us all. I regained the self-assurance to return to school and the following year was offered a job by the Ontario HIV Treatment Network (OHTN), a partner in the PSHP research project. I was hired as a project coordinator; one of my projects was to help oversee the next phase of the PSHP research study. I was overjoyed with the job offer and couldn't believe what opportunities had opened up for me since being involved in community based research. However, with this first full-time job

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Welcome to Camp Goodtime

By John Coady

Camp Goodtime aims to provide medical updates, psychological, social and peer support, consultation and education to reduce the social and geographical isolation affecting families living with HIV.

Camp Goodtime is an annual four-day volunteer camp with the Paediatric HIV Service at Sydney Children's Hospital. It is part of a national support network for families living with HIV. This article describes the camp's programs available to both parents and children, including leisure activities, workshops, and social events.

The camp also provides feedback from fathers of the children, based on a 2007 research project to evaluate the capacity of fathers' group programs. These programs were initiated in 2003 to develop peer support and self-support management strategies for continuing care once the families leave the camp.

Camp Goodtime aims to provide medical updates, psychological, social and peer support, consultation and education to reduce the social and geographical isolation affecting families living with HIV. It provides a recreational and therapeutic environment where families from around Australia can share valuable experiences with others in similar

situations. Psychosocial issues such as stigma, discrimination, disclosure, marginalisation, social isolation, the changing nature of HIV management and long-term care are addressed within a safe, semi-structured environment.

Most years since 1990, the camp has supported about fifty parents and sixty children. Trained volunteers are matched to children, giving both parents and kids some respite. Informal specialist medical and allied health information is offered to the parents, with discussion focused on medical updates, medication, pregnancy, dental care, or sexual health and teenagers. There are workshops for the parents, with separate groups discussing

particular issues. Some shared meetings cater for all parents, including a 'get to know you' at the start of camp and a remembrance ceremony that honours friends and relatives who have died.

The kids are allocated into age groups for activities with the volunteers. The kids are busy with activities such as water-sliding, boating, rock-climbing, canoeing and negotiating ropes courses. Some activities are available for parents too, such as creative writing, meditation, yoga, and producing the camp HIV/AIDS Quilt. There's time for parents to catch up, plus a night out to socialise and a theme party for the families.

For many families affected by HIV, this is the only opportunity they have to connect with other similarly affected families. They come from all over Australia, with some having attended camp for up to fifteen years. In 2007, 26 families attended with 27 women, 14 men and 48 children representing all States and territories except NT. The camp was held in a National Park on the outskirts of Sydney, with families from interstate cities and regional areas. They come from a range of cultural backgrounds. They all are different, yet share HIV in common. Here, they don't have to censor themselves and are free from the secrecy of their daily lives.

An opportunity for research

The epidemiological pattern of HIV/AIDS in Australia has meant that services have largely been targeted at gay men, their partners and families. At that time, up to 90 percent of infection rates affected homosexual men, with less data then available regarding heterosexual transmission. From 2002–2007 the pattern has changed with consistent heterosexual infections reaching 21 percent of new HIV diagnoses.¹ There have been many HIV studies into priority populations such as gay men and intravenous

drug users. However, in regards to the lived experiences of positive heterosexuals, recent studies have noted an absence of narrative and qualitative research², 'indeed the very concept of heterosexuality is largely absent from much of the language, media and educational material in the Australian HIV sector'³.

HIV Camp Goodtime focuses on these clients, with the majority of the men identifying heterosexually, with their wives, partners, children (biological, step, fostered, and adopted) making up this unique client group. However, little research data on Camp Goodtime exists as to the efficacy of the service. In regards to families with children, specific programs such as Camp Goodtime remained untouched by formal social research. Apart from a published camp review⁴, fundraising, promotional activities and appraisals have relied on the annual evaluation garnered by the service.

It was my wish to evaluate the service and to acknowledge the courage of the participants as they highlight the

diversity of families affected by HIV/AIDS. A Pilot Study, consisting of a qualitative survey was followed by a recorded interview. This study was reviewed and with recommendations from the participants, a questionnaire was developed for the fathers attending the camp.

We asked a range of questions of the fathers in ascertaining the benefits of the camp and in particular the group programs that had been developed over the previous five years. We asked their age, postcode, and family description; how often they had attended and how long HIV had affected their family. We wanted to know why they attended camp, the range of services available and whether they noticed any service changes. We asked whether they found the new group programs helpful or not. We wanted to understand what impact these services had for the fathers, their families and within their communities.

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All fourteen men were invited to fill out the questionnaire. Ten completed the survey and accepted a 45-minute interview. Four men who were new attendees, declined the survey, preferring to provide feedback via the evaluation process. Participants ranged in age from forty-one to sixty-three years, though most were in their forties.

Findings

Connection

It was found that the groups have helped break down barriers between the fathers. The formal meetings lead to informal connection, and 'it's more rewarding when you have those private conversations for the remainder of the camp'. The men lacked the ability to 'converse as the women do':

'It's allowed us to be more open with each other, willing to broach subjects with someone you didn't previously know.'

An opening now exists for ongoing discussion with their peers, with continued information and support from the long-term attending fathers:

'Some of the guys I'd known for quite a few years at this stage and we'd never discussed some of these things'; and 'My perception has changed about how I view HIV/AIDS.'

Social Isolation

'Back home we don't have much to do with anybody else around, so we're mostly on our own. It means a lot to come here and meet other people. You get to know the fathers, hearing bits and pieces and realised we're all saying the same thing, the same feelings. That was important because you realise you are not alone.'

One father said it took him a while to attend the group. He and his wife were focused on their kids, often keeping to themselves, but learned something when he attended the fathers' meetings:

'I didn't come to the group initially, and didn't contribute as I was sitting

listening in those days. And then, you realise you're not the only person with the same fears and everything'.

So, from sharing their experiences, the fathers understood their stories were similar. They were encouraged to share and by telling their story, the process became inclusive:

'I get a different thing out of it even if we cover the same ground, it makes me feel good'; and

'It keeps me afloat and I know I'm not alone; it gives me more confidence.'

Stigma and discrimination

Living with stigma and discrimination remains a central issue. Sometimes they experienced this from professionals. One father described his wife not being allowed into the school grounds when she dropped off the kids. On another occasion, an HIV health counsellor presumed particular behaviours as the reason some of the men contracted HIV, "as drug users or closet gays" as one respondent described his experience. Fathers spoke of the resultant isolation towards the kids with parents' disclosure to schools. The children's friends were forbidden to interact with them:

'Most of our friends we used to have cut themselves off from us because of their paranoia and it basically left us [totally] on our own.'

Secrecy becomes part of their lives but allows them more freedom in connecting with others:

'Most of the year you keep it all inside'; 'The only venue for them to discuss issues was at the camp'; and

'It helps cope with the cynicism and prejudice we sometimes receive from the public sphere.'

Conclusions

'I thought it was just for the kids'.

The reasons for the fathers attending camp were varied but primarily for the kids enjoying themselves. Over time however, by sharing their experiences

they developed a relevant space for themselves with aims and outcomes. They have become the mentors for the new dads attending. The program structure and familiarity with the the same social worker (over a five year period) assisted with group identity, cultivating their voice, culminating in:

"... allowing us old hands to be more active in helping new people share their stories and experiences".

The research has provided data that validates and highlights the value of Camp Goodtime and the group programs. The connections the fathers have made and now acknowledge is illustrated in new knowledge and confidence that they integrate from their camp experiences:

'I've become stronger for my partner; my fear of losing her has diminished'; and 'As I am HIV negative and my partner is HIV positive, she is grateful that I have someone to speak to.'

There is a genuine acceptance that issues discussed at camp result in some normality, where the input:

'allows our home life to continue more normally as things get dealt with at camp.'

For further information, please contact Angela Miller on 02 9382 1851.

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A glimmer of hope for microbicides

By Jason Appleby and Abigail Groves

PRO 2000 (polynaphthalene sulphone) is a microbicide candidate currently being tested in several trials to determine its efficacy at preventing HIV infection. Recent results indicate that a gel containing PRO 2000 may have a “30 percent effect against HIV”, though researchers warn that this result is not statistically significant. This is the first microbicide to demonstrate a positive result in a large study.

Microbicides are chemicals that can be incorporated into gels, foams or devices that can be used in the vagina (and potentially the rectum) to prevent HIV transmission during sex. A number of previous studies in women in sub-Saharan Africa have failed to show a protective effect of microbicide candidates, including Carraguard and cellulose sulphate (UsherCell).

The HPTN 035 trial was conducted by the Microbicide Trials Network. It involved 3099 women and was conducted between February 2005 and September 2008 in Malawi, South Africa, Zambia, Zimbabwe and the United States. The results of this study were presented at the 2009 Conference of Retroviruses and Opportunistic Infections (CROI) in Montreal.

The study compared the effects of PRO 2000 gel, a placebo gel, no gel, and BufferGel, a buffering agent designed to maintain normal vaginal acidity in the presence of ejaculate. Studies have shown that HIV is inactivated below a pH of 4 to 5.8. During the course of the study, 194 infections occurred: 36 infections among women using PRO 2000 gel, 54 infections among women using the BufferGel, 51 infections among participants who used the placebo gel, and 53 infections among participants who used no gel.

PRO 2000 prevented about a third of potential infections in women who used it, compared with women in the other trial arms. Because women who used high levels of gel might

also be frequent condom users, the investigators then compared infection levels in women who used high levels of both condoms and gel versus women who used few condoms but often used the gel. In this latter group, whose protection against HIV solely or mainly consisted of gel, there were three infections in 299 women who used PRO 2000 (incidence rate 1 percent) and 15 infections in 324 who used placebo (incidence rate 4.6 percent). This meant that 78 percent of infections in non-condom users appeared to be stopped by PRO 2000.

The potential efficacy of PRO 2000 raises implications both for HIV prevention efforts and for future research. The product is relatively cheap and would not be difficult to incorporate into standard prevention efforts. However, if the product is only 30% effective, there is a risk that the limited protection it offers would be offset by declining condom use. PRO 2000's efficacy as a rectal microbicide was not evaluated, and this is a question that would need to be determined if it was released for broader use.

The results of the HPTN 035 study are encouraging, but further evidence of efficacy is required before this product is considered for wide scale use. The trial only evaluated the efficacy of preventing HIV transmission in women due to vaginal intercourse. A larger study of PRO 2000, the UK-funded MDP 301 study, is due to announce results later this year and will be able to demonstrate efficacy if similar reductions in HIV infections are found.

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Challenges in HIV vaccine research and development in the 21st Century

By Dr P. Jeyarathan

HIV vaccine researchers believe that an HIV vaccine would be the best weapon to eradicate the epidemic because no viral disease has ever been controlled without a vaccine.

The AIDS pandemic is one of the greatest public health threats in the world since the 16th century. HIV vaccine research scientists believe that a vaccine is the only way to halt the epidemic. The development of a safe, effective, and cheap preventative vaccine will be a daunting task for the foreseeable future. Unfortunately, recent attempts to create a vaccine have proven unsuccessful. Some vaccine candidates, despite success in animal models, showed an unexpected increase rather than decrease in the rate of HIV transmission.

Introduction

Since 2000, billions of dollars have been spent on HIV vaccine research without sign of an effective vaccine. HIV vaccine researchers believe that an HIV vaccine would be the best weapon to eradicate the epidemic because no viral disease has ever been controlled without a vaccine.

HIV is the best-studied pathogen in the world and has only nine genes compared to bacteria (500) and humans (20,000–25,000). But it is still unclear to scientists what approach will work

to develop a vaccine. Initially, much of the focus was concentrated on the identification of immunogens that would elicit neutralising antibodies at a high enough concentration to prevent infection (Johnson and Fauci, 2007). However this strategy has been unsuccessful, largely due to the fact that HIV demonstrates extreme genetic diversity. One HIV strain inside one individual is capable of generating more variants than the global strains of H1N1 influenza virus can generate in a year.

Despite its genetic simplicity, HIV is a complex virus. It has the ability to target and destroy the components of the immune system that a vaccine would normally trigger. The virus evades the immune system by undergoing rapid change. HIV also lacks the corrective 'proofreading' capacity of other viruses. This lack of "proofreading" contributes to the genetic diversity that HIV demonstrates (more than 100 million variants during the final stages of the infection).

There are other scientific challenges to HIV vaccine development: What is the most effective approach, or combination of approaches, that would trigger an immune response HIV at the cellular, humoral or mucosal levels? And finally, can a single universal vaccine create immunity against the different subtypes, or clades, of HIV, or will a different vaccine be needed for each subtype? In addition, uncertainty exists as vaccine candidates which have worked successfully in animal trials have not displayed the same success in human trials.

The Holy Grail in HIV vaccine research would be the discovery of a vaccine which would protect against transmission by different mucosal routes and be able to neutralise all different subtypes and clades.

Progress

HIV vaccine research efforts have targeted a protein called glycoprotein 120 (gp120) which resides on "external surface" of HIV, making it more accessible to vaccines. Recent concept trials of this vaccine failed to protect healthy individuals against HIV infection (Flynn *et al.*, 2005; Pitisuttithum *et al.*, 2006). It was thought that people immunised with a vaccine that induced a T cell response could not prevent HIV infection, but they might be able to reduce the initial viral load after infection.

It is thought that low viral loads immediately after infection might be associated with slower progression of disease (Craib *et al.*, 1997; Lefrere *et al.*, 1998). Three thousand participants took part in a 2007 trial to test this but interim analysis showed that vaccine had no effect at all. It neither prevented HIV acquisition nor reduced the initial viral load despite stimulating the T cell response (Steinbrook, 2007; Merck, 2008).

The failure of the gp120 vaccine lead to other vaccine development options being considered:

1. **DNA vaccines:** these vaccines are safe because the vaccines do not contain all the genes of HIV. Therefore, participants/volunteers will not get HIV infection. They use isolated HIV genes to trigger a cell-mediated immune response. It is important to note that many of the current HIV vaccine candidates are DNA vaccines.
2. **Combinations of vaccine candidates:** HIV vaccine research scientists have designed combination regimens. Scientists think combinations of different designs, strategies, or immunogens will produce a broader spectrum of immune responses. Several combinations are now being tested in clinical trials, including but not limited to canarypox plus gp120 (Phase III); DNA plus MVA (Phase II); recombinant adenovirus plus canarypox (Phase I); canarypox plus lipopeptides (Phase I); and DNA plus protein (Phase I). (Tonks, 2008). (See Figure 1.)

Where are we going?

Despite all the difficulties, obstacles and setbacks, HIV vaccine researchers are working on a number of problems:

1. Many vaccine candidates work by neutralizing the virus with antibodies. Scientists have not yet

discovered ways to elicit antibodies that neutralize the different strains of HIV globally.

2. The Merck Vaccine trial (2008) has provided insights into HIV cell-mediated immunity (CMI). It is evident that inducing effective CMI responses will be more challenging than originally thought.
3. Much of the focus of the HIV vaccine clinical research has been on vectors and delivery systems for vaccine candidates (or immunogens). Researchers need to determine the optimal immunogens for eliciting cell-mediated immunity.

There are now about 30 HIV vaccine candidates in clinical testing. It is hoped that most of them, if not all, will trigger (at least partially) the immune system. The main objective is to delay or prevent HIV disease. (See Table 1.)

Conclusion

It is a fact that although significant progress has been made in HIV vaccine research since 2000, no vaccine has yet been found. According to Dr Alan Bernstein of the Global HIV Vaccine Enterprise:

"No individual, no country will develop a vaccine alone"; and he added "global challenges require a global approach".

According to Mitchell Warren, co-chair of the satellite conference, (AIDS, 2008, Mexico City):

"Coordinating HIV vaccine research and development efforts to contribute to the goals of the Global HIV Vaccine Enterprise is a far greater challenge for humanity than sending a man to the moon".

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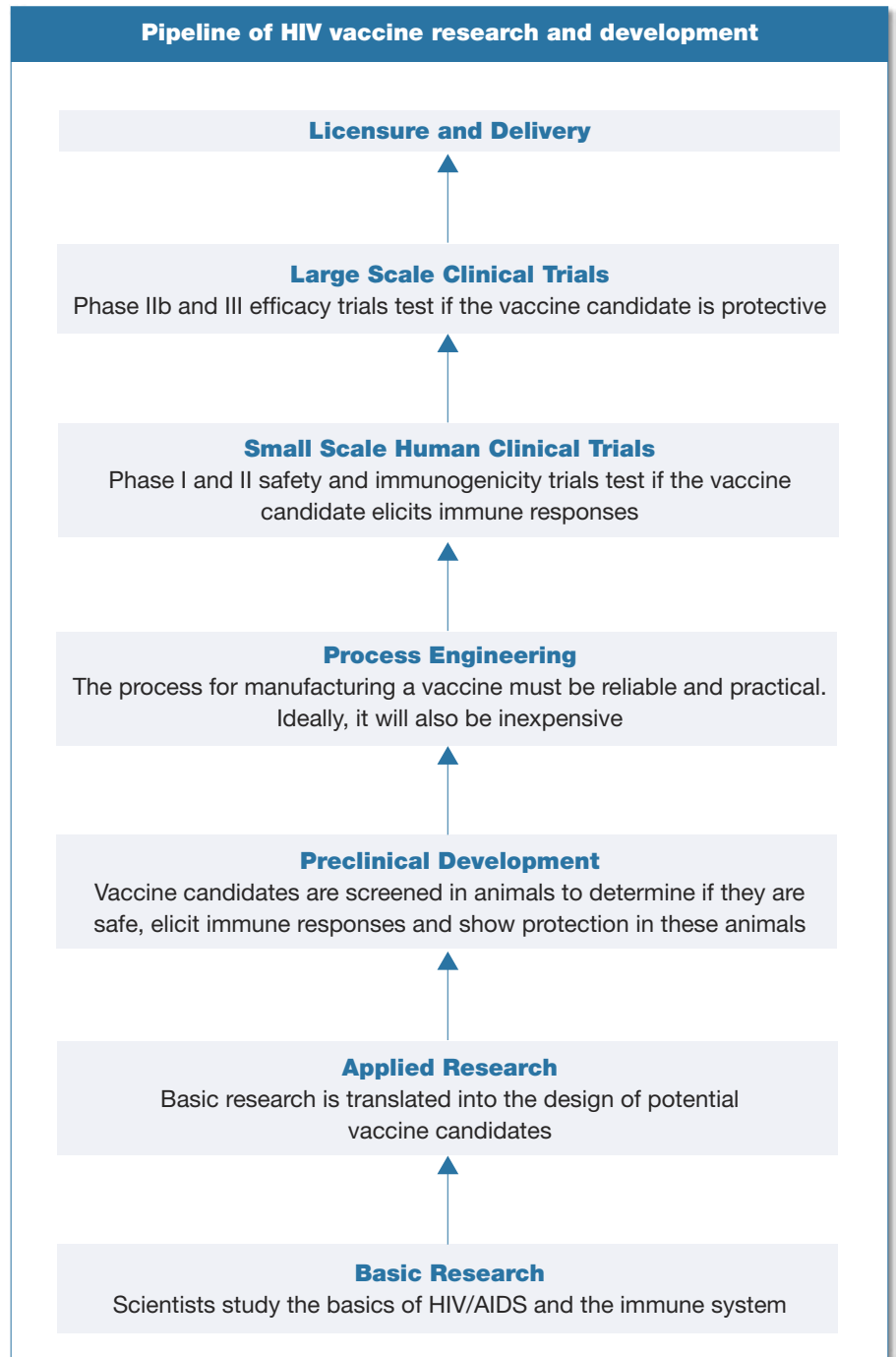


Figure 1 Pipeline of HIV vaccine research and development. © Ann McDonald Cacho, adapted from www.iavi.org

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Table 1 AIDS Vaccine Candidates in Clinical Trials

Protein Prime + Vector Boost	Phase III
Canarypox Clades B, E, gp120 prime	US Department of Defense, Ministry of Public Health Thailand, National Institute of Allergy and Infectious Diseases, ThaiAIDS Vaccine Evaluation Group, sanofi Pasteur, VaxGen
DNA Vectors +/- Vector Boost	Phase I/II
Clade B'C + Electroporation	International AIDS Vaccine Initiative, Ichor, Aaron Diamond AIDS Research Centre
DNA ployepitopic, MVA boost	Epimmune Pharmexa, Bavarian Nordic
Clade B, MVA boost	GeoVax, US Military HIV Research Program
Multiclade A, B, C, MVA boost	Karolinska Institute
Clade B'C, MVA boost	Johns Hopkins University, Guangxi, Changchun Baike
Clade C, NYVAC boost	EuroVacc, Agence national de recherches sur le sida et Le hepatitis virales
Clade B + 1L-12, 1L-15, peptide boost	Wyeth
DNA Clade C, MVA boost	South African AIDS Vaccine Initiative
DNA Clade A, E, FPV boost	The HIV Netherlands Australia Thailand Research Collaboration
Pennvax-B	University of Pennsylvania, VGX Pharmaceuticals
Viral Vectors	Phase I/II
Adenovirus	
Ad-6 Clade B	Merck
Ad-35 Clade A, +/- Ad-5 (prime or boost)	National Institute of Allergy and Infectious Diseases, Vaccine Research Centre
Ad-26 Clade A	National Institute of Allergy and Infectious Diseases, Harvard University
Pox	
ALVAC-HIV	National Institute of Allergy and Infectious Diseases, sanofi Pasteur
MVA Clade A, E	Walter Reed Army Institute of Research
MVA Multiantigen	Bavarian Nordic
MVA Clade C	International AIDS Vaccine Initiative
Vaccinia multiclade (DNA & Protein cocktail)	St. Jude Children's Research Hospital
Proteins	Phase I/II
Gp140 Clade C <i>mucosal</i>	St. George's University of London
C-terminal p17, full p24, fragment of gp41 with polyoxidonium adjuvant	Institute of Immunology, Moscow
Adjuvanted Gag, Pol and Nef	Glaxo Smith Kline

Source: AIDS vaccine blueprint 2008, International AIDS vaccine initiative



Australian Federation
of AIDS Organizations

napwa



ARE YOU REALLY SURE HE'S HIV NEGATIVE TOO?

If he has fucked without condoms since his last HIV test, he may have picked up, and be passing on HIV.

One-third of all new HIV infections come from men who don't even know they are HIV positive.

Some of the people most likely to pass on HIV may not even know they have it.

If you can't be sure of his HIV status, use condoms and lube.



Regional Snapshot: Cambodia's HIV response and Australia's contribution

By John Godwin

The epidemic is also emerging among men who have sex with men (MSM) and injecting drug users, and there is significant overlap among drug users, sex workers, and men who have sex with men.

Fragile gains?

Cambodia's HIV response has gained a reputation as a success story. Prevalence among adults was estimated to be 0.8 percent in 2007.¹ Ten years earlier, it was the country with the highest HIV prevalence in Asia, with adult prevalence over 2 percent. But it is worth keeping in mind that deaths, as well as reductions in new infections, contributed to the decline in prevalence. The number of people living with HIV was estimated at 75,000 in 2007.²

Sex work largely determined the course of the epidemic in the 1990s. An aggressive campaign of condom promotion with sex workers and clients led to a decline in HIV prevalence among sex workers from a peak of 45.8 percent in 1998 to 12.7 percent in 2006. However, there remains a risk of a resurgence of the epidemic among sex workers, their clients and other

sexual partners. Police implementing trafficking laws introduced in 2008 have targeted brothels. Sex workers are now forced work on the street and bars, and as a result NGOs have reported difficulties in reaching sex workers with prevention services.³

The epidemic is also emerging among men who have sex with men (MSM) and injecting drug users, and there is significant overlap among drug users, sex workers, and men who have sex with men. Married women are emerging as a new population at risk, with HIV being transmitted by clients of sex workers to their regular partners. As many as 70 percent of MSM also have sex with women.⁴ Women now represent more than half of people living with HIV and between a third and a half of new infections are in married women.

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Unlike many other countries in the region, drug use has not been a major driver of the epidemic over the last decade. However, this may be set to change as illicit drug use in Cambodia is on the rise, particularly crystal methamphetamine. In 2007, 35.1 percent of injection drug users in Phnom Penh were HIV-positive, an increase from 14 percent in 2006.⁵

In 2005, HIV prevalence among men who have sex with men was 5.1 percent nationally and 8.7 percent in Phnom Penh.⁶ Among transgender populations in Phnom Penh, HIV prevalence was an alarming 36.7 percent in 2000.⁷ Yet there are very few programs for these populations.

National response

The national response is coordinated by the National AIDS Authority (NAA) and its Secretariat within the framework of the National HIV/AIDS Strategic Plan 2008–2010.

The National Plan emphasises targeted prevention with most at-risk populations, positive prevention and increased access to PMTCT services.

The civil society response is coordinated through the HIV/AIDS Coordinating Committee, which has a membership of 90 NGOs. The Ministry of Labour and Vocational Training has mandated HIV workplace training in private

enterprises which is supported by Trade Union Federations.

NGOs have played a central role in the national response, particularly in reaching marginalised communities and championing peer based approaches. Funding for prevention with drug users, transgender populations and men who have sex with men has been limited. From 2009, funding from the Global Fund will enable expansion of services for sex workers, drug users and men who have sex with men, including harm reduction and implementation of a national plan to address needs of men who have sex with men.

Donor landscape

The Global Fund, USAID and the UK Government's Department for International Development are the largest donors to the HIV response. UN agencies such as UNAIDS, UNDP, UNICEF, UNODC and WHO also play an important role.

USAID and DFID are jointly funding a five-year program of support to the Ministry of Health's National Program in HIV and Sexual and Reproductive Health. The USAID/DFID program has a focus on social marketing and behaviour change.

AusAID is a relatively small donor. AusAID is commencing a new harm reduction program addressing injecting

drug user needs in partnership with the Cambodian government in 2009. This assistance is to be provided as a component of AusAID's HIV/AIDS Asia Regional Program (HAARP).

NGOs and community-based groups

There are dozens of NGOs working in HIV. Important local NGOs include Khmer HIV/AIDS NGO Alliance, Cambodian Red Cross and the Reproductive Health Association of Cambodia. Korsang works with drug users and prisoners. The Cambodia Network of People Living with HIV (CNP+) is coordinating positive groups in all provinces and has established the Cambodian Community of Positive Women. The Women's Network for Unity is a sex worker group conducting advocacy and peer education.

International NGOs with HIV programs include CARE, Marie Stopes International, Population Services International (PSI) and Family Health International. International NGOs working on treatment and care in Cambodia include Clinton Foundation, Médecins du Monde and Médecins Sans Frontières.

Australian NGO and research partnerships

AusAID funds the HIV Capacity Building Program to link Australian organisations to Indonesian partners. This program funds a Consortium of Australian organisations to implement the following activities:

- **The Australian Federation of AIDS Organisations (AFAO)** works in partnership with the Asia Pacific Council of AIDS Service Organisations to strengthen the advocacy capacity of community-based organisations in Cambodia.
- **The Australian Injecting and Illicit Drug Users League (AIVL)** has a partnership with Korsang and is working with Korsang in

Unlike many other countries in the region, drug use has not been a major driver of the epidemic over the last decade. However, this may be set to change as illicit drug use in Cambodia is on the rise, particularly crystal methamphetamine.

supporting the development of national drug user network and a regional network of people who use drugs.

- **Scarlet Alliance** is supporting Cambodian sex worker organisations to attend regional training opportunities and to develop networks with other peer-based groups in the region.
- **The National Centre for HIV Social Research (NCHSR)** at the University of New South Wales (UNSW) and **Australian Research Centre in Sex, Health and Society** at La Trobe University are partnering with universities and researchers in Phnom Penh on training and other capacity building activities.
- UNSW's **National Centre for HIV Epidemiology and Clinical Research (NCHECR)** is implementing a field research training program with partner institutions, establishing mentoring relationships and supporting the development of a national HIV research network.
- Australia's **National Serology Reference Laboratory (NRL)** is supporting an External Quality Assurance System for Cambodian laboratories.

Australian development NGOs

- **Save the Children Australia** provides support to orphans and children living with and affected by HIV through a community-driven programme that provides food parcels, transport for medical care, access to education and individual counselling and advice.
- **CARE Australia** supports orphans and vulnerable children with vocational training, care, counselling, and legal support. CARE is also supporting government facilities that provide antiretroviral therapy and is

implementing a sex worker-led HIV prevention program at Cambodian-Thai border sites.

- **Australian Red Cross** supports HIV interventions focused on the casino industry and integrates HIV into other programs, such as water and sanitation.
- **Caritas Australia** provides social support such as housing and employment, training and education.
- The University of Melbourne's **Nossal Institute** has been providing technical assistance for the development of a national monitoring and evaluation framework for Cambodia's HIV response.

Adding value?

Cambodia's response has been heralded as a success, and this had been built on a foundation of national political leadership on HIV. The challenges for Cambodia in sustaining this success are, however, considerable. Cambodia is one of the poorest countries in the world, and is managing many other serious health threats apart from HIV. Although Cambodia's epidemic and health economy is very different to our own, Australian organisations are adding value to the national response in a number of important niche areas

including in technical, advocacy and community development approaches.

Australia is a relatively minor player in the overall development scene in Cambodia, and plays on a very crowded field of HIV donor projects. Nonetheless, Australian partners have the opportunity to support the Cambodian government, NGOs and communities to develop more effective approaches to reach the most marginalised communities at the frontline of a fast changing epidemic.

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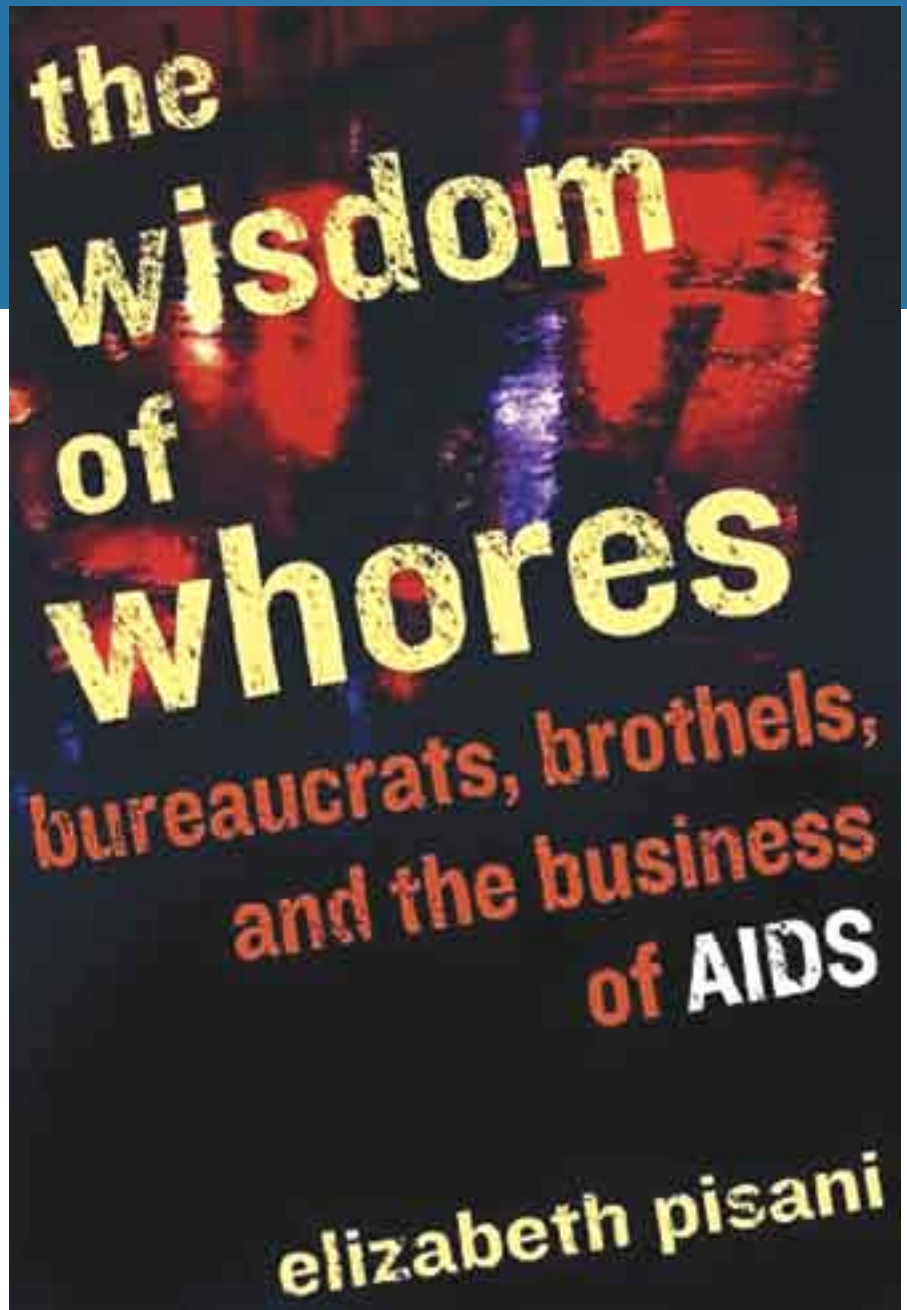
Book review: *The wisdom of whores* by Elizabeth Pisani

Reviewed by Kira Magee

The Wisdom of Whores is the newest literary endeavour by journalist-gone-epidemiologist, Elizabeth Pisani. The book takes place over the 10 years of Pisani's epidemiology career and looks at the spread of HIV and HIV prevention programmes in South East Asia, particularly Indonesia.

Pisani writes with humour, fiery wit and determination. This leads to quite convincing arguments in calling out the so called sacred cows of HIV/AIDS treatment and prevention strategies such as mandatory testing, international intervention, and survey strategies. Unfortunately, it is using this confident tone that she smoothly and unabashedly uses language one would not expect from someone on the street, let alone someone supposedly on the front lines of HIV prevention programs. She uses nicknames such as "toilet junkie". She opines on whether or not Indonesian *Waria* (Indonesian female transgendered sex workers) should get surgery on their genitals. This is at times both offensive and completely unnecessary, and could be construed as speaking from a place of comfort within these communities – which, as a white, ex-journalist, non-sex-working female, she is simply not a part of, but merely studying.

Addressing issues such as independent vs. government funded HIV intervention and international donor money, Pisani makes no apologies for prescribing to the 'for the good of the many' way of thinking. Analysing so-called smaller 'boutique' programs providing top service to a small amount of people vs. mediocre services for a wider group, Pisani does well to go into depth describing processes and bureaucracies involved in funding and applications. But she then goes on to discuss such areas as peer education



stating, "[h]elping other people deal with HIV can work well for infected people too. It can give people a sense of purpose they didn't have when they were out trawling the nightclubs every evening." It is easy to understand why, although informative and smart, Pisani's writing makes it easy for members of any community which is her subject group to be left feeling used, belittled and misrepresented.

While bold and sometimes offensive, the book talks in depth about where funding comes from, existing social networks, misinformation, alternative prevention methods and needle exchange programs. So *The Wisdom of Whores* is definitely filled with enough information, analysis and

question-raising to not make the book a complete write off. Unfortunately, Pisani's attempt to balance the book with overall sentiment of 'we are all at risk' falls short and in the end disintegrates with every use of the term 'junkie' and every demonisation of sex workers. These ignorant remarks make it more and more difficult to find the rest of the book unbiased, credible or even interesting.

While worth reading, this reviewer and whore thinks Pisani needs to gain more wisdom about the impact she may have on the groups of which she seems so fit to capitalise off.

Kira Magee is a Sydney-based sex worker and activist

WEB WATCH

Over the coming months *HIV Australia* will feature a new section, 'Web Watch', which aims to highlight websites, blogs and other online resources relating to HIV issues. We encourage reader input. Send suggestions of your favourite HIV-related sites to editor@afao.org.au



'Criminal HIV Transmission' is an online weblog (or 'blog') that documents and monitors current thinking and emerging legal precedents relating to the criminal prosecutions involving HIV transmission.

The blog is maintained by UK author and blogger Edwin J Bernard. Bernard has been writing about HIV for many years, both as a freelance commentator and as an editor for periodicals including *HIV treatment updates* and

the *aidsmap* website. Bernard is also currently the treatments editor for the UK publication *Positive Nation*, so he is well placed to moderate a forum about the issues.

The 'Criminal HIV Transmission' site is regularly updated to provide comprehensive coverage of global breaking news and access to resources about criminal prosecutions of HIV transmission. Stories and resources are well laid out and the language

used is clear and accessible. Bernard is a passionate advocate against most of the prosecutions he documents, so his commentary is frequently fairly vitriolic. He is vehemently opposed to the criminalisation of HIV transmission, with the exception of cases where it can be proved beyond any doubt that intentional transmission actually occurred (so therefore not just cases where the person was aware of their positive HIV status). Accordingly, as is the nature of many blogs, the site could not be said to be free of personal bias.

'Criminal HIV Transmission' also provides facilities to search by both comprehensive keyword and by country, so it is very easy to find information relating to specific jurisdictions or interest areas. Overall, the blog is therefore a great resource for anyone interested in keeping abreast of current information about these issues.

Bernard keenly encourages reader feedback and input about criminal cases, although he states that comments which could be deemed 'offensive, libelous or potentially prejudicial to cases' will not be published. He invites reader contributions and comments via email at Edwin@edwinbernard.com.

HIV AUSTRALIA

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When to start treatment: leave it no later than 350, major studies agree

Two very large cohort studies published in April both agree: antiretroviral treatment should not be delayed after the CD4 count falls below 350, reports **Keith Alcorn**. However, the two studies show contradictory evidence on whether starting treatment before the CD4 count falls below 500 has an additional benefit. Both studies were presented at the Sixteenth Conference on Retroviruses and Opportunistic Infections in February.

The When to Start Consortium analysed 22,444 patients and found a significantly greater risk of AIDS or death in those who started treatment with a CD4 count below 350 cells/mm³, but no additional reduction in the risk of death if people started treatment at CD4 counts above this level.

The North American AIDS Cohort Collaboration on Research and Design analysed 17,517 patients and found that the risk of death was 94 percent greater in those who deferred treatment to a CD4 count below 500 cells/mm³ compared to those who started treatment with a CD4 count above 500 and 69 percent greater in those who deferred treatment to a CD4 count below 350 cells/mm³ compared to those who started in the range 350–500.

Editorials accompanying both publications agree that the only way the field of HIV treatment will reach a definitive conclusion on the question of when to start antiretroviral treatment will be by carrying out a large randomised trial of immediate versus deferred treatment. A major study is

planned by the US National Institute of Allergy and Infectious Disease.

In the interim, Australian guidelines currently recommend that treatment should start when the CD4 count falls to around 350 cells/mm³. World Health Organization guidelines for resource-limited settings recommend that where CD4 counts are available, treatment should start before the CD4 count falls below 200 cells/mm³, with consideration given to treating patients with a CD4 count below 350 cells/mm³.

FDA cautions that Kaletra should not be used by patients with heart rhythm problems or underlying heart conditions

Drug regulatory authorities in the United States have updated the product labelling of the protease inhibitor Kaletra (lopinavir/ritonavir), warning that it should not be prescribed to individuals with either heart rhythm problem or any underlying heart problems, reports **Michael Carter**. Reports have emerged that treatment with Kaletra could cause some types of irregularities in the rhythm of the heart.

Atazanavir (Reyataz) can also cause this abnormality in heart rate, as can a number of other drugs including calcium channel blockers, beta-adrenergic blockers, and digoxin. The FDA warns that caution is required if any of these drugs are used with Kaletra. Caution is especially important if any of the drugs are, like Kaletra, processed by the body using the CYP3A pathway in the liver.

Dr Mark Nelson of the Chelsea and Westminster Hospital told *aidsmap.com* that these revisions were “not too big a deal” and noted that similar heart rate problems had been associated with “atazanavir and possibly other protease inhibitors.” Should irregularities in the rhythm of the heart develop, however, he recommended that these should be taken very seriously.

Treatment intensification does not eliminate HIV in reservoir sites

HIV persistence and treatment intensification were themes running throughout February’s Sixteenth Conference on Retroviruses and Opportunistic Infections in Montreal. **Liz Highleyman and Edwin J. Bernard** reported on research findings that HIV continues to be released in small amounts from “reservoir” sites in the body, despite suppressive antiretroviral therapy, and adding more drugs has not succeeded in eradicating the virus.

Now that combination antiretroviral therapy can suppress HIV replication, researchers have begun to revisit the question of viral eradication. This exploration is aided by more sensitive viral load tests that can measure down to a single copy of HIV RNA. Researchers debated whether small amounts of residual HIV are due to low-level ongoing viral replication allowed by current antiretroviral drugs or whether they are released from stable reservoir sites.

But studies that added more drugs to regimens or intensified them did not reduce or eliminate residual HIV as was hoped. Siliciano went on to argue that given that residual virus is genetically similar and does not exhibit evolution, it is likely to come from stable genetic material in reservoir sites rather than ongoing replication, as antiretroviral therapy stops viral evolution in adherent patients. “Progress toward eradication of the infection will require novel approaches to target the stable reservoirs that persist even when viral replication is completely halted,” Siliciano concluded.

Simultaneous treatment of HIV and TB improves survival

Starting treatment for both HIV and tuberculosis at the same

time lowers the risk of death by around 65 percent, in comparison with deferring HIV treatment for at least three months, report Spanish investigators in the February 1 edition of *Journal of Acquired Immune Deficiency Syndromes*. **David McLay reported** that the finding adds evidence to the current debate around co-treatment of the two infections.

In people co-infected with HIV and active tuberculosis (TB), treatment of the TB infection is a priority. However, questions remain as when to start HIV therapy. The main argument for early treatment is the risk of HIV disease progression. Arguments for delayed treatment include the risk of immune reconstitution syndrome, interactions between anti-HIV and anti-TB drugs and the large number of pills people need to take when they are taking both treatments together.

Current WHO guidelines recommend early treatment in people with low CD4 cell counts and delayed treatment for those with stronger immune systems. A group of Spanish investigators used data from almost 7,000 HIV-positive people treated in five hospitals in Madrid and found that patients who died were more likely to have received deferred HIV treatment, to be injection drug users, have an earlier year of diagnosis of TB and HIV and have another AIDS-defining illness. Starting HIV and TB therapy at the same time improved survival with simultaneous treatment being associated with around a 65 percent decreased chance of death, even with other factors taken into account.

While the investigators could not conclude that this was not the result of some unknown confounding effect, their findings suggest improved survival by using concomitant TB and HIV therapy that seems independent of other factors. Further research is warranted, they recommended.



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It would be a courageous government that decided to abandon their current involvement and funding of HIV services, but it is a possibility. This approach would disconnect the policy process from the understanding of people most affected by HIV and AIDS. What is hard to demonstrate is the likely consequences on the course of infection rates. Would they advance at a more rapid pace and how different would that pace be to the current increasing infection rate?

Abandonment of the current model can be made to appear rational and palatable. HIV funding could be redirected to the proposed new national prevention agency to be established by the federal government¹², or to a broad Sexual Health Strategy aimed at the whole community. These are defensible propositions in times of increasing deficits, but would fundamentally change the nature and focus of HIV organisations over time.

The partnership response to HIV in Australia is likely to experience the result that derives from policy

inertia – nothing much will change. The partnership will continue as an important symbol of how Australia responded well to the challenge of AIDS and will continue to receive similar levels of money and access to policy processes. It will fall to the community sector to keep the response to HIV vital in the minds of policy makers. HIV organisations will have to maintain a vibrant and trusting relationships with those most at risk of HIV infection. Funding will continue to decline, as the perceived threat of HIV to our lives, our economy and our communities recedes. One of the most difficult policy problems of the success of the Australian response to AIDS is the difficulty of demonstrating what we have achieved and how many infections and deaths have actually been avoided.

It has been twenty years since every parliament in Australia considered *“AIDS: A Time to Care, A Time to Act”* and during those decades the partnership has evolved into an accustomed method of progressing our response to HIV. However, we

need to acknowledge the relative change in the urgency of AIDS as a public policy problem. The communities most directly affected by HIV have to continually, vigorously and cleverly argue the case for ongoing effort and partnerships based on real equality. To let the Australian response wither, is to accept an ever-expanding burden of disease and death that HIV delivers over time. This burden is unacceptable in economic, social and human terms. It is a legacy we cannot leave for future generations.

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Ian Rankin is a resident of Canberra and is a former president of both the Australian Federation of AIDS Organisations (AFAO) (2005–2007) and the National Association of People Living with HIV/AIDS (NAPWA) (1996–1997)

The partnership response to HIV in Australia is likely to experience the result that derives from policy inertia – nothing much will change. The partnership will continue as an important symbol of how Australia responded well to the challenge of AIDS and will continue to receive similar levels of money and access to policy processes.

structures and previous national strategies, and what are the areas for improvement. There was seen to be a need for improvement around national leadership, in HIV, hepatitis C, STIs, and Indigenous sexual health. A need for more clarity about the role of the Ministerial Advisory Committee. And a need to ensure that the partnership approach, which has been so successful, is re-energised and valued, to ensure that the strategies are widely owned and are also monitored, so we can see what changes are occurring as a result.

I think all that feedback has been very helpful and it's very clear that the Minister and the Commonwealth Department of Health and Ageing have been very cognisant of the feedback in development of the new structure, so that's really positive.

You've also recommended that young people be involved in the writing of these new strategies. Do you see that as a strategy for revitalisation?

Absolutely. Look, I think that capacity building is incredibly important and I'm really keen that we have the opportunities for young people to get involved in the writing and development of the national strategies, and some of the working parties that will be established under the new national committee. Not just to be there to gain experience of being involved in this sort of work, but to have a very real voice and to inform the rest of the committee about what the important issues are for young people in Australia around these particular conditions.

We're dealing with a very significant generational change, particularly around the impact of the internet. We know that the majority of people under 30 in Australia tell us that they get most of their important information

through the Internet, rather than from other sources. And, of course, this is going to be the way that many of the important health messages need to be disseminated as well. I'm really enthused about the way the Minister has embraced the concept of engaging more young people into the process.

What do you see as the priorities for the next National HIV Strategy?

I'm not going to pre-empt what the reference group for the writing of the strategy says, because I want people to be able to bring forward the ideas, priorities and imperatives that they think are most important. But clearly we still need a strong focus on groups of people within the community who are at increased risk of HIV infection. We still need strong attention to treatment and care and support issues for people with HIV. There are also some significant issues around the global epidemic and its impact on Australia, with an increase in numbers of Australians who have contracted HIV in other countries. We have significant epidemics occurring on

Australia's doorstep, for example in neighbouring countries like Papua New Guinea.

I think it's fair to say that after the new treatments became available in this country, we took our collective foot off the accelerator with regard to education – particularly targeted, explicit education campaigns to get across the health promotion messages that need to be got across to those at risk. And, as we know, education needs to be presented in a variety of different formats, through a variety of different media in many different ways so that you ensure that the key messages about prevention are getting out to everybody who needs to hear them. I'm sure that the new strategies will have a very strong focus on the education aspects of prevention.

Abigail Groves is the Editor of HIV Australia and Policy Manager at AFAO.

We're dealing with a very significant generational change, particularly around the impact of the internet. We know that the majority of people under 30 in Australia tell us that they get most of their important information through the Internet, rather than from other sources. And, of course, this is going to be the way that many of the important health messages need to be disseminated as well.

people are often moving through high-level leadership roles across a relatively insular sector, was neither sustainable nor useful in the longer term. As one person put it, the leadership, “has been around for a long time, and although they have contributed significantly to the body of knowledge, they are increasingly reluctant to change and challenge the rhetoric.”

While acknowledging that many leaders have brought about significant changes in a period of significant hardship, there was the perennial concern of how to retain the “corporate history”, activist skills and established networks embodied within individuals and in the response as a whole.

This was often articulated as being in conflict with desires to cultivate innovation and the new enthusiasm of emerging leaders. This “failure to establish a space which mentors and inspires people” was described as having its own “internal personality clashes” and being “too caught up in the power plays between organisations.”

Few of the interviewees could reconcile the fact that both retention and renewal are required, and many interviewees struggled to define how this balance could be achieved. This is where those working within the sector and those no longer involved

differed greatly. Whereas interviews with those currently working in the sector were more apt to identify a need for both renewal *and* retention of leaders, including “breeding new talent internally” – those no longer involved in the sector most often reflected upon a sector wanting for urgent renewal and “new blood.”

This urgent call for ‘renewal’ (as a combination of renewal of the existing leadership and the incorporation of new leaders) should not be ignored and it is a matter for the current leadership to address in relation to developing future leaders and a long term sustainable response. Building the capacity to change and meet the evolving expectations of communities requires the same passion and commitment which was required early on in the epidemic. It also requires the humility and insight to ask the systemic questions of continued relevance, usefulness and the preparedness of current leaders to respond to change – personally, professionally and practically.

Many of the interviewees spoke of the strength and imperative of leaders to listen to community and to other leaders in the field. They saved their harshest criticisms for the leadership’s failure to listen, identify, mentor and

create spaces for new leaders to emerge within the response itself.

Empowering new leaders in any field takes courage – especially from those in positions of power and leadership. Firstly it means having open, accessible and transparent succession plans for key positions. Very few, if any, interviewees could identify leadership succession strategies within the community HIV response. As one interviewee commented, “far too often, succession is something that happens out of fortune or consequence – neither being preferable.”

There was a common agreement that a diversification of responses to community issues and a diverse leadership to guide these responses is urgently required. As one interviewee described, “the irreconcilable tensions [of a leader] between being part of a ‘community’, and part of a ‘response’”. Such an example was illustrated in reference to recreational drug use. Conflicts will arise when leading a discussion regarding the risks of drug use in a community where drugs are a significant part of the social fabric. There will be tension between the understandable desire not to further stigmatise gay culture or community and the desire to minimise any harm to individuals or the community as a whole.

There was also the suggestion that the “crisis activist response” by leaders and the organisations they lead is limited (although not without its uses). Leaders need to focus upon the sustainability and durability of their organisations and the subsequent programs and services they provide.

A surprising number of interviewees suggested the need for fewer organisations which had more clearly defined mandates – many spoke of a more “streamlined response” and the need for leaders to consider this downsizing or collapsing of functions as a mechanism to maintain relevance. As one person

A surprising number of interviewees suggested the need for fewer organisations which had more clearly defined mandates – many spoke of a more “streamlined response” and the need for leaders to consider this downsizing or collapsing of functions as a mechanism to maintain relevance.

said, “there is an urgent need to locate our organisations in the salient spots of community engagement.”

There were a number of suggestions as to how the current leadership could reinvigorate and rejuvenate the response, such as:

- reconsidering the governance structures of organisations to allow emerging leaders to participate more fully
- challenging identity-based representational policies, procedures and practices to instead focus upon gathering talented AND trained people into leadership roles
- opportunities to debrief the complexities of living and working in an identifiable “community” as a leader in a sometimes insular sector
- appreciating the specific tensions for people who have HIV and, at the same time, the need to be clear-headed advocates for a wide group of people
- encouraging “deep questioning” which includes fostering dissent and acknowledging the diversity, difference and difficulty required to successfully work on seemingly intractable problems.

The way forward

From such a wide range of interviews came an equally wide range of suggestions on how to move forward as a sector. Much was said about the current structural impediments for changing and moving forward and even more about keeping pace with change in communities.

Many of the interviewees spoke of the need for future leaders to be more competent in the areas of business and governance. They identified that, as HIV is no longer just a community health issue but a public health concern, a more professionalised response is required. Some people argued that the increasing professionalism of leaders would lead to greater accountability

and more effective outcomes, but also articulated a longing to consider the history of a ‘grassroots’ involvement and the need for truly effective leaders to continue to harness the community in the response; the “need to reinvigorate the role of the volunteer.”

As people spoke of the need for a diverse response to the issues, they also spoke of the need for a more diverse approach by leaders and more diverse leaderships styles and to “engage with the controversy that connects with identity.”

Leading a professional response to HIV in Australia while at the same time identifying and building the capacities of new leaders is challenging, but not impossible. It will mean that some investments in supporting emerging leaders may fail. Some leaders, when ready to take on the mantle of leadership, may decide not to; leadership succession plans do not always follow according to design.

Amongst all of this, new issues arise, situations change and contexts expand – both for individuals and communities. However, without articulated, transparent, and strategic investment in future leaders, renewal is constantly usurped by retention. Striking a balance between professionalism and community involvement is as possible and as important as ensuring programs exist to ensure mentoring of future leaders by the current leadership.

Conclusion

There was clear consensus that new leaders need to evolve into roles and positions of authority. Celebrating new leaders’ accomplishments and mentoring leaders means more than providing access to skills and experience – it means providing time and opportunity for emerging leaders to learn and reflect under the guidance of others.

For future leaders to be “fearless” and “passionate advocates”, they require

a firm footing in the history of the response. They need those who have experienced these aspects of leadership to share with them the aptitudes and challenges of being a leader in the response. This means learning from current and past leaders and forming their own leadership style or signature which reflects the current complexities with vision and insight.⁷

Perhaps the bravest of all leaders are those that know when to step aside – allowing new life, new ideas and new growth to develop – assured that it is the paths they have forged that will pave the way for the leaders of the future.

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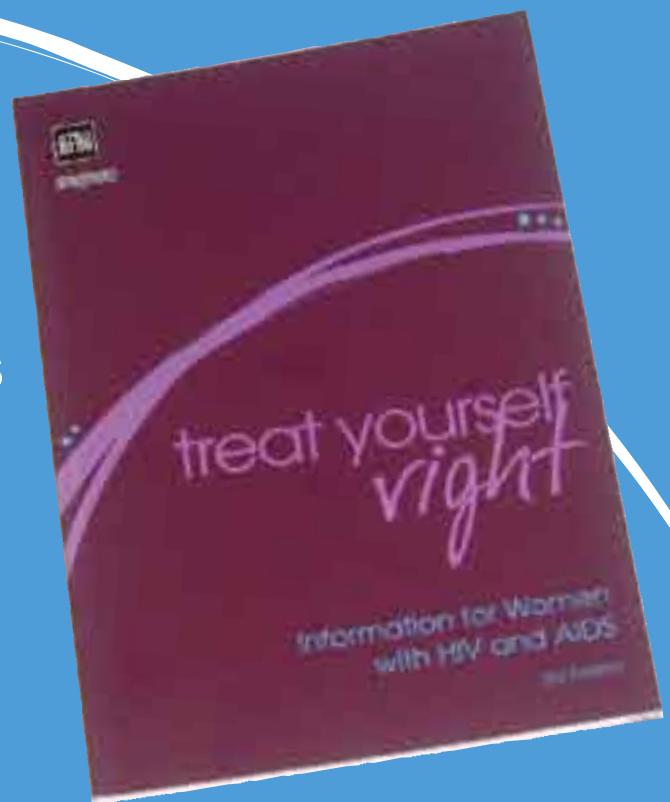
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Brent Allan has worked in the HIV sector both in Australia and abroad since 1990 and has held positions at ACON, VAC/GMHC and NAPWA.

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to show. Following a long decline, the annual number of new HIV diagnoses in Australia has steadily increased over the past eight years, from 718 cases in 1999 to 1,051 in 2007.

The profile of the Australian epidemic and the required response is also changing. In the past five years, sixty percent of cases of HIV infection attributed to heterosexual contact were among people from high HIV prevalence countries or their sexual partners.¹⁴ In 2009, we see an increasing number of cases of people being prosecuted for HIV infection, and a sudden increase in the rate of new infections among heterosexual men who have acquired HIV while working or holidaying overseas. Who knows what the next decade will bring?

Managing the diverse priorities and perspectives of positive people is no easy matter. Frequently, goals are competing and debates are intense. Some people have been distressed and disappointed by arguments and 'splits' that have occurred but as long as the process is well managed, diversity of opinion is not problematic *per se*. In fact it is crucial:

*As often as they converge, unite, and rally around one issue, HIV communities can differ, disconnect, and fight over another. ... There simply is no one HIV community and no one perspective.... Instead, HIV communities bring to the dialectic an especially rich menu of perspectives rooted in the lives of their constituents. This is the perfect recipe for doing excellent public health.*¹⁵

How do we make Positive Leadership a reality?

Around the world, analysts are recognising an impending leadership vacuum in the response to HIV/AIDS, and they are starting to organise. The 2008 International AIDS Conference in Mexico City included a Leadership Program. Prior to that meeting, nearly 400 HIV-positive people from 88 countries

met at the 2008 Positive Leadership Summit to organise their participation in the 2008 International AIDS Conference and set their strategic agenda for a comprehensive response to the AIDS pandemic.

In Australia too, agencies are organising to ensure the next generation of leaders are equipped to meet impending challenges. In July 2008, NAPWA embarked on a new initiative: a residential Leadership Weekend. NAPWA is currently finalising its Positive Leadership Report, due for release in April 2009. Stay tuned.

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Sally Cameron is a Consultant and former Policy Analyst at AFAO.

In 2009, we see an increasing number of cases of people being prosecuted for HIV infection, and a sudden increase in the rate of new infections among heterosexual men who have acquired HIV while working or holidaying overseas. Who knows what the next decade will bring?

in many years came apprehension and a new set of challenges. Although promised support, I felt out of my depth and unsure of myself. Was this the beginning of another phase of the capacity building process or the end? Was I still under the protective wing of supportive educators or now a “regular” employee with all of the expectations of that role? I was surprised at my level of stress over possible failure.

What I may have needed was mentoring. I brought unique and important skills to my new job, but what I didn't have was the confidence to hit the ground running by myself (or experience with a photocopier!). If a capacity building framework is not built in to an organization's mandate, it may be challenging to offer professional support for the inexperienced. I argue that if capacity building is to succeed in the long run, without inadvertently setting a person up for failure, support and training opportunities need to be in place throughout the transition from

part-time contract work to unfamiliar full-time work. A detailed plan of support needs to be actualised for PLHIVs, so that well-earned feelings of self-efficacy and self-esteem are sustained. I had been instilled with the gentle and more holistic values of CBR capacity building, and my understanding of this process collided with the “real world” structure of corporate hierarchy and employee/ employer expectations.

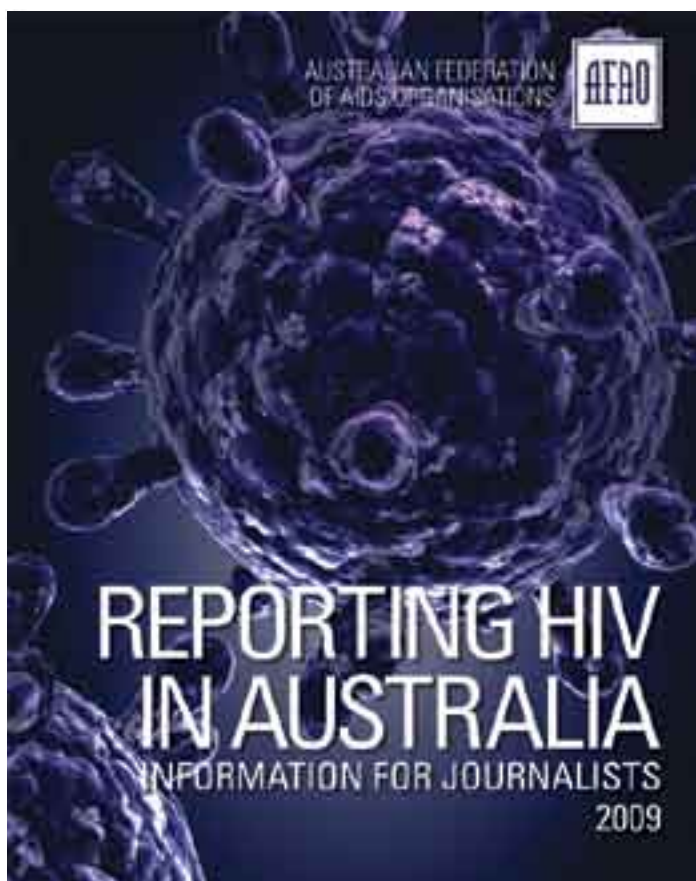
I have had moments of concern about the effectiveness of PLHIV capacity building and its ability to support lasting full-time employment. If CBR capacity building is ultimately to succeed, there needs to be buy-in and coordinated planning from all organisations with a stake in the future health and well being of PLHIVs. It has been a difficult personal progression at times, but I fully support CBR and the capacity building that it can provide. Thankfully, the OHTN, where I am a Research

Coordinator, is taking a leading role in Ontario by initiating the development of a Peer Research Training Institute, where diversity, career support and sustainability are at the forefront of its vision. The future looks bright for capacity building in my province as we progress with PLHIVs not as passive recipients, but as equal partners.

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James Watson is the Community Research Project Coordinator at the Ontario HIV Treatment Network in Toronto, Canada.



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EXPERIENCED
FLU-LIKE
SYMPTOMS,
FEVER, RASHES...?**

If he has had sex without condoms since his last HIV test, he may have picked up, and be passing on HIV.

One-third of all new HIV infections come from men who don't even know they are HIV positive.

Some of the people most likely to pass on HIV may not even know they have it.

If you can't be sure of his HIV status, use condoms and lube.