

**HIV**  
**AUSTRALIA**

**HIV and ageing: a changing epidemic**

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**AFAO's aims are to:**

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

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AFAO is the peak non-government organisation representing Australia's community-based response to the HIV epidemic. 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.

This edition of *HIV Australia* looks at people's experiences of growing older with HIV and examines the synergies between HIV, antiretrovirals and age-related conditions.

**Cover:** *Old Boots* by Guy Pascoe.

Guy Pascoe attended an art class facilitated by Liz Brown in 2009 at the Positive Living Centre in South Yarra. He did not have a subject in mind, so took off his boots and painted them. Guy is currently completing a Bachelor of Fine Arts at NMIT. This image could be said to represent his journey, and that of many others living with HIV, who have suffered stigma, discrimination, grief, and poverty – having travelled the long road and endured the hard journey with courage and dignity in the face of adversity.

— Lizzi Craig, Victorian AIDS Council (VAC)/ Gay Men's Health Centre.

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# HIV AUSTRALIA

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## AFAO welcomes Sydney injecting centre certainty

According to the Australian Federation of AIDS Organisations (AFAO), best practice public health policy has finally won out with the announcement on 15 September that the Medically Supervised Injecting Centre in Sydney's Kings Cross will be made permanent.

AFAO Executive Director Don Baxter congratulated the NSW Government on its decision. 'This decision by the NSW Government will save lives and is simply the logical, evidence based outcome from the mountain of medical evidence collected over nearly a decade ... As a facility for harm-minimisation and to prevent the transmission of HIV the (centre) has been an outstanding success. The so-called 'War on Drugs' approach has clearly failed and it is time we moved to treating drug use as primarily a health issue rather than primarily a criminal issue', Mr Baxter said.

## Circumcision call

Calls for a return to circumcision as a standard practice would only help prevent the spread of HIV among heterosexual men, not gay men, reported Andrew M Potts in the *Sydney Star Observer* (Tuesday, 21 September 2010).

Potts' article was in response to an article in the *Medical Journal of Australia* (MJA) by St Vincent's Hospital's Dr Alex Wodak, National Centre in HIV Epidemiology and Clinical Research Director David Cooper and Sydney University Molecular Medical Sciences Professor Brian Morris, in which the benefits of circumcision were discussed.

The authors noted in the MJA article that data from developing nations where HIV was widespread showed circumcision reduced the risk of males catching HIV from females, suggesting countries with far lower HIV rates could benefit too. 'Being a low-prevalence country does not preclude a population-wide approach to HIV prevention ... we test pregnant

women to prevent cases of vertical HIV transmission. Infant male circumcision would be a comparable, albeit more interventionist, population-wide strategy', they said.

Australian Federation of AIDS Organisations executive director Don Baxter suggested caution on circumcising male infants as a means of preventing HIV: 'There needs to be thorough discussion about the impacts and the value of moving in this direction, particularly in light of the nature of the epidemic in Australia where it is overwhelmingly among gay men and remains around seventy percent so,' Mr Baxter said.

Mr Baxter said there was little evidence to suggest circumcision did much to prevent HIV transmission in gay men, though it was somewhat protective against human papillomavirus (HPV). However, a vaccine was available for HPV which could be made available on the Pharmaceutical Benefits Scheme.

In response to the MJA article, Dr Gervase Chaney, a member of the Royal Australasian College of Physicians' Committee for Paediatric Physician Training, told *Sydney Star Observer* that realities around HIV in Australia were very different to those in developing nations.

'The College does not believe the African data can be directly extrapolated to the Australian or New Zealand circumstance as HIV and other sexually transmitted infections have a much higher prevalence in Africa', Dr Chaney said.

Dr Chaney said there were also ethical issues to consider when 'clearly an infant is unable to consent to a procedure', and that efforts to educate heterosexuals about the risks of HIV infection would produce better outcomes.

## Nursing home wins award for GLBT policies

Riviera Health, an Australian aged-care provider, has been working in conjunction with community groups to develop culturally appropriate care and

services, and initiated a project looking at issues underpinning the provision of residential aged-care and service to lesbian, gay, bisexual, transsexual and intersex people.

This work has now been recognised with an award – the Anita Villa nursing home in Katoomba, run by the Riviera Health group, winning the 'strategy to promote the mental health and wellbeing of residents with special needs' category in this year's Positive Living in Aged Care Awards organised by the Aged and Community Services Association of NSW and the ACT.

Riviera Health's Dr Michele Chandler told Andrew M Potts of the *Sydney Star Observer* they were proud of winning the award:

'A lot of providers in aged-care have a religious basis, so to get this acknowledged when it's a taboo subject is really important ... We were getting a lot of enquiries from people in same-sex couples who were seeking aged-care and were quite frightened about what that might mean', she said.

For Riviera Health, the changes have been good for their bottom line. 'People are saying, "If they can look after the LGBT community and let them be themselves, we can go there and be ourselves too"', Chandler said.

## Blood donor policy review

The Australian Red Cross Blood Service has commissioned a review of current policies relating to the screening of potential blood donors with regard to sexual activity. The review will consider deferral policies for men who have sex with men, including the questions potential donors are asked, in the light of scientific evidence, and international practice.

Organisations and members of the public are invited to make submissions to the Review Committee addressing concerns and providing suggestions regarding Blood Service deferral criteria relating to sexual activity. The Review Committee will provide independent advice to the Blood Service. The details of the review and submission process can be found at [www.bloodrulesreview.com.au](http://www.bloodrulesreview.com.au). The deadline for submissions is 6 November, 2010.

# NEWS FROM THE ASIA PACIFIC

## Crunch time for universal access to HIV treatment

In the lead-up to the Global Fund's Third Voluntary Replenishment and pledging conference in New York on 4–5 October, the Asia Pacific Network of People Living with HIV (APN+) and the Communities Delegation on the Board of the Global Fund urged global leaders and donor countries to seize the critically important opportunity to progress moves towards universal access to HIV treatment, care and support.

Shiba Phurailatpam, Regional Coordinator of APN+, anticipated that the Global Fund meetings would be critical to ensuring universal access: 'Global leaders need to step up and demonstrate leadership and accountability in ensuring HIV, tuberculosis and malaria are addressed through a innovative financing mechanism that has produced country-led responses and in real partnerships with civil society and affected populations ... The view of civil society across the Asia Pacific region is that the Global Fund needs US\$20 billion if real progress is to be made', he said.

APN+ produced a video to raise awareness of the need for Global Fund to show practical commitment – available at <http://www.globalfundreplenishment.org>. The video was released to coincide with public demonstrations, press conferences and others actions held across the African continent as well as the US, Canada, Italy, Russia and other countries.

Forceful advocacy by APN+ and global community networks met with some success – donors meeting in New York pledging US \$11.7 billion to the Global Fund to Fight AIDS, Tuberculosis and Malaria for the years 2011–2013 – but the commitment falls well short of the U\$20 billion APN+

believes is required if universal access to HIV treatment, care and support is to be achieved.

## Voice of youth

Supported by UNAIDS and the World AIDS Campaign, the Dutch NGO Hivos organised the first Asian-Pacific regional MSM and transgender and HIV Youth consultation in Bangkok in early September, with 40 young MSM and transgender people from 14 countries attending.

Held over three days in Bangkok, the group discussed key issues for young people, including prevention, self-esteem, and access to relevant and appropriate services, information and education. A major focus was discussion of human rights abuses of young men who have sex with men (MSM) and transgender people in the region, and participants presented recommendations for action to international partners.

'Young voices – and particularly ours – have not been heard for the longest time in the AIDS response. It is crucial we become empowered. Now we have a forum where young MSM and transgender can really contribute – this is very important', said Hender Gercio, a student and HIV activist from the Philippines.

James Gray, Australian Youth Ambassador for Development working with the UNAIDS Regional Support Team in Bangkok, also emphasised the importance of young people finding voice and influence: 'The consultation represents a timely opportunity to reflect on the struggle that many young MSM and transgender people face in advocating for and taking control of their own health, particularly concerning HIV and sexual health ... This is an important step towards strengthening the response by creating a space for this

group to be involved in a meaningful way', he said.

As a result of the consultation, further resources will be made available to support MSM youth groups in the region. The group will continue to share experiences, and will reconvene in 12 months.

## Philippines to distribute contraceptives

The Philippine government 'will provide contraceptives to poor couples who request it, despite strong opposition from the dominant Roman Catholic church' to which more than 80 percent of the country belongs, *Agence France-Presse* reported on 26 September.

President Aquino said during a visit to the United States last week: 'The government is obligated to inform everybody of their responsibilities and their choices. At the end of the day, government might provide assistance to those who are without means if they want to employ a particular method ... I believe the couple will be in the best position to determine what is best for the family, how to space (the births), what methods they can rely on and so forth.'

Catholic Church representatives have criticised Filipino President Aquino's support for contraception, the Associated Press (AP) reported on 28 September. The Reverend Deogracias Yniguez of the Catholic Bishops Conference of the Philippines told AP, 'The whole church is against it'. Presidential spokesman Edwin Lacierda responded that 'Aquino is willing to sit down with church officials to explain his position, which promotes 'responsible parenthood', AP reported.



## 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](mailto:editor@afao.org.au)



# INTERNATIONAL NEWS

## Donors commit US\$11.7 billion to the global fund for next three years

Donors meeting in New York have made a US \$11.7 billion financial commitment to the Global Fund to Fight AIDS, Tuberculosis and Malaria for the years 2011–2013. The new funding compares with US\$9.7 billion committed to the Global Fund in Berlin in September 2007 for the period 2008–2010.

More than 40 countries, the European Commission, faith-based organisations, private foundations, and corporations committed funding at the pledging session in New York.

Resources promised this month will enable already approved programs to continue and significantly expand their current efforts. In addition, at least US\$2.9 billion will be available for new commitments in the next three years. However, the total pledges fall short of the estimated resources needed to meet demand from developing countries seeking to further scale up their disease programs.

‘I deeply appreciate the efforts of all the public and private donors who with this replenishment have shown their continued confidence in the Global Fund’, said Michel Kazatchkine, the Executive Director of the Global Fund. ‘However, we need to recognise that this amount is not enough to meet expected demand. It will lead to difficult decisions in the next three years that could slow down the effort to beat the three diseases. I will continue a relentless effort to seek the additional resources the Global Fund needs to fully contribute towards achieving the Millennium Development Goals.’

Among the 40 donor countries at the New York meeting, the Australian Government announced a 55% increased commitment to the Fund, totaling A\$210m over three years. Don

Baxter of the Australian Federation of AIDS Organisations (AFAO) welcomed this announcement, but stressed that increases should not stop: ‘The overall pledges by the richer countries fall well short of the Global Fund’s target of \$20 billion and the \$11.7 billion pledged will mean HIV prevention and treatments programs will fall further behind the pace of the virus.’

Baxter said that that urgent interventions must be made to address rampant HIV and STI epidemics amongst men who have sex with men living in Asia’s densely populated, poor ‘mega-cities’. He noted that, although the current Australian Government AusAID HIV Strategy prioritises this concern, the current funding allocations do not reflect this urgent priority. ‘We are calling on the government to inject a further \$30m over five years into prevention and support programs addressing sex between men in our near Asian neighbours’, Baxter said.

## Universal access to HIV/AIDS services a possibility?

Significant progress has been made in several low and middle-income countries in increasing access to HIV services, according to a new report, *Towards universal access*. The report – produced by WHO, the UNICEF and UNAIDS – is the fourth annual report for tracking progress made in achieving the 2010 target of providing universal access to HIV prevention, treatment and care. The report assessed progress in 144 countries in 2009.

WHO believes that progress in Eastern and Southern Africa, the region most severely affected by HIV, offers hope; HIV treatment coverage in the region increased from 32% to 41% in 2009, with 53% of pregnant women able to access HIV testing and counselling in that year. Despite this ‘hope’, Jimmy Kolker, Chief of HIV and

AIDS of UNICEF, is focussed on the challenges ahead: ‘Every day, more than 1,000 infants acquire HIV ... We know how to prevent this ... intensified efforts are urgently needed to reach all mothers and children with the most effective treatment ...’, he said.

Dr Paul De Lay, Deputy Executive Director, Programme, UNAIDS, pointed to the fundamental issue of financing. ‘We’re on the right track, we’ve shown what works and now we need to do more of it ...’

## Russia’s escalating HIV epidemic

The Russian government has announced a dramatic increase healthcare funding, reported Diana Markosian in *Rianovosti* (27 September, at en.rian.ru). However, although Russia proposes to invest more than \$430 million in global healthcare before 2012, it is clear that not everyone is convinced of its commitment to dealing with root causes of health issues, including those affecting HIV prevention among injecting drug users.

Anya Sarang, president of the Andrey Rylkov Foundation for Health and Social Justice, is one of the doubters. Sarang points to Russia’s refusal to adopt ‘internationally proven’ means of treating opiate addiction, such as methadone, in the belief that the West’s policy of supplying methadone to addicts exacerbates the problem. It similarly disapproves of needle exchange programs, claiming that they are a tacit approval of the low level crime that funds users’ habits.

According to *Rianovosti*, over the years NGOs have plugged enormous gaps that the Russian government has failed to fill. A five-year grant provided by the Global Fund to Russian Health Care Foundation expired at the end of August last year, resulting in the defunding of more than 40 prevention programs, most of them targeting injecting drug users. As this edition of *HIV Australia* was going to press, the Global Fund had not approved new funding, claiming Russia is no longer eligible for HIV funding.



# Launch of the Michael Kirby Centre for Public Health and Human Rights

By Michael Williams

The **Michael Kirby Centre for Public Health and Human Rights** – which sits within Monash University's School of Public Health and Preventive Medicine – was officially launched on Sunday 29 August 2010 by Michel Sidibé (*pictured above with Michael Kirby*), Executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS).

The launch, held at the Positive Living Centre in Melbourne, was attended by over 250 people and hosted by Bryan Dawe. It attracted many distinguished guests from the judiciary, academia, medicine and non-government organisations.

Mr Sidibé spoke about his deep admiration for Michael Kirby and the immense contribution he has made over many years in combating HIV/AIDS. Speeches were also delivered by the Centre's Director, Associate Professor Bebe Loff and Diane, a

former sex worker and injecting drug user. Diane pointed to her own experience to emphasise that ignorance of human rights by state agencies can have catastrophic consequences for vulnerable groups already at risk of poor health outcomes.

The Centre's namesake, the Hon Michael Kirby AC CMG, spoke movingly about the history of HIV/AIDS and the auspicious appearance on the global scene of the late Professor Jonathan Mann, a figure widely credited with recognising the importance of human rights in responses to HIV. Kirby said that 'it is that linkage which the [Centre] will seek to explore, chronicle and further'. He promised to maintain a 'close, ongoing relationship' with the Centre going forward.

The Michael Kirby Centre will critically examine the role that human rights standards can play in public health

policies and interventions and is the first of its kind in Australia. Assertions that human rights are good for health need to be better founded, theorised and more rigorously translated into practice. While HIV is the paradigm disease which illustrates this link, due to its prevalence among vulnerable groups typically lacking rights, the Centre's work is broader than HIV. The Centre's Bebe Loff and Dr Deborah Zion were recently nominated for an Australia Museum Eureka Award for their work examining the ethical duties of health professionals caring for asylum seekers in detention.

The Centre's current projects include a four year study on how regulatory environments in Australia contribute to the obesity epidemic and what reform to these structures might look like; a project on what Australians think about privacy in the conduct of health and medical research; and the creation of a legal service in Cambodia to improve the human rights and health of sex workers. It will soon embark on a global mapping of laws and enforcement practices which affect sex workers across 20 countries, and its researchers are engaged in theoretical studies on what constitutes 'justice' in the context of healthcare. The Centre also undertakes law and ethics teaching to international health professionals. Although while the Centre is primarily a research body, it also aims to incorporate its research into programs on the ground.

Impressed with its potential to contribute to the mission of UNAIDS in articulating the link between health and human rights, Mr Sidibé proposed a formal memorandum of understanding between UNAIDS and the Michael Kirby Centre to work in partnership.

**For further information about the centre, visit <http://www.med.monash.edu.au/michael-kirby/>**

**Michael Williams is a Research Fellow at the Michael Kirby Centre for Public Health and Human Rights. Cheryl Overs is a Senior Research Fellow at the same Centre.**

# Antiretroviral (ARV)-based prevention

By Dean Murphy

## Microbicides

The big news in biomedical prevention at the Vienna conference was the much-anticipated release of efficacy data from the CAPRISA 004 trial of a vaginal microbicide, containing 1% tenofovir, among women in South Africa. The results were announced with much fanfare and excitement at a special conference session, despite the fact that they had already been released by one media organisation a day earlier.

The study found tenofovir gel reduced HIV infections by 39%, a finding that is statistically significant. HIV incidence in the tenofovir gel arm was 5.6 per 100 person-years of study observation, compared with 9.1 per 100 person-years in the placebo gel arm (incidence rate ratio = 0.61;  $P = 0.017$ ).<sup>1</sup> There was a trend towards higher effectiveness – a 54% reduction – among women who reported higher adherence. (Women were requested to insert one dose of gel within 12 hours before sex, and a second dose of gel as soon as possible within 12 hours after sex – with no more than two doses of gel in a 24-hour period.)

Also, the HIV incidence rate in the tenofovir gel arm, when compared with the placebo gel arm, was 50% ( $P = 0.007$ ) lower after the first 12 months of follow-up – which may indicate greater adherence in the first year of the study. In another very

positive finding, the study found that use of the gel reduced the risk of herpes simplex virus 2 by 51% among women participating in the trial.

There were no significant safety concerns identified with the gel. The vast majority of the participants (97.4%) found the gel acceptable. Among the women who seroconverted while using the gel, there were no changes in viral load and no tenofovir resistance.

## ARV therapy as prevention

Despite the lack of any big announcements, ARV therapy as HIV prevention was an important theme at Vienna, with several sessions devoted to this topic.

Julio Montaner argued that ARVs have already demonstrated their efficacy in HIV prevention, based on his analysis of data from British Columbia, Canada.<sup>2,3</sup> Between 1996 and 2009, the number of individuals receiving combination ARVs increased from 837 to 5413 – a significant increase of 547%. During the same period, the number of new HIV diagnoses fell from 702 to 338 per year, a 52% decrease. The overall correlation between the number of people on ARVs and the number of people newly testing HIV-positive per year was  $-0.89$ , indicating a significant association ( $P < 0.0001$ ). For every 100 additional

people on ARVs, the number of new HIV cases decreased by a factor of 0.97, or by 3%. For each 1 log decrease in viral load, the number of newly diagnosed HIV cases decreased by a factor of 0.86.

In the same session Geoffrey Garnett presented on a model that examined the potential impact of treatment initiation at different CD4 levels (i.e. at either  $< 200$  or  $< 350$ ) on HIV transmission in a generalised heterosexual epidemic. The model also examined the potential synergies of PrEP and ARVs for preventing HIV transmission.<sup>4</sup> Results showed that, with good coverage of ARV therapy, 25% of new infections could be averted if treatment is initiated at  $CD4 < 200$ , and an additional 15% of infections averted if treatment is initiated at  $CD4 < 350$ . Reductions in risk behaviour associated with treatment could improve this; increases in risk behaviour could undermine it. PrEP can reduce incidence but needs high efficacy, coverage and adherence – and needs appropriate targeting to be efficient. That means for the same number of people starting PrEP, effective targeting to those at most risk can substantially amplify impact. However, earlier initiation of ARV therapy reduces the potential role of PrEP; and PrEP's effectiveness per partnership relative to treatment of the infected partner determines how useful

it would be in discordant couples. At least 60% PrEP efficacy is needed for PrEP to avert more infections than ARV therapy in serodiscordant couples.

Myron Cohen pointed out that observational studies of treatment as prevention in serodiscordant couples have shown mixed results.<sup>5</sup> Although the findings have mostly been positive, a recent Chinese study (Wang, *JAIDS* in press) has shown negative results with reported seroconversions being evenly distributed among couples in the treated and untreated arms.<sup>6</sup> In addition, even in studies where ARVs have reduced the risk of HIV transmission by up to 80%, the risk of HIV transmission was not completely eliminated.<sup>7</sup>

Cohen provided a criticism of mathematical models of ARVs for prevention, and suggested that the results are predicted by the assumptions factored into such models. To demonstrate this he provided examples of seven published models. Those with assumptions of high treatment coverage, adherence, and no increases in risk behaviours showed positive results (with one exception), and those with assumptions of increased risk taking showed negative results. However, moving away from modelling studies, Cohen also showed how ecological studies have provided mixed results. Some studies, such as the British Columbia study discussed above (as well as other studies from San Francisco and Denmark), have suggested a positive effect of ARV therapy on HIV epidemics, whereas studies from Amsterdam, France and Sydney have shown no such effect.

Cohen also examined what he referred to as the 'inconvenient truths' of transmission during acute and early infection, and the possibility of transmitted drug resistance. The latter is seen, according to the published model by Granich et al., at moderate levels of adherence.<sup>8</sup> Cohen's conclusion was that ARVs have the power to reduce onward transmission of HIV, but the magnitude and durability is unknown. The population benefit of ART will depend on the durability of transmission suppression, preventing

## WHAT NEXT FOR MICROBICIDES?

**The VOICE Study (MTN-003) is evaluating the safety and effectiveness of two ARV-based approaches for preventing sexual transmission of HIV in women, as well as determining whether these women are more likely to follow a regime of applying vaginal gel daily or taking an ARV tablet once a day.**

The CHARM (Combination HIV Antiretroviral Rectal Microbicide) Program, among women and men who have sex with men (MSM), will test rectal gels containing tenofovir and a new ARV drug called UC781 (both separately and in combination) for safety and efficacy.

The MTN 017 trial is a Phase II, multi-site, open label crossover study of adherence and pharmacokinetics of oral and rectal formulations of tenofovir among 120 men in Thailand, Peru, and the US. This will possibly roll-over into Phase IIB/III efficacy trial.

transmitted resistance, and dealing with acute HIV infection.

In an earlier conference plenary session, Bernard Hirschel, one of the authors of the Swiss Consensus Statement, argued that 'all things being equal' the ten years from 2000 to 2010 would have seen 50–100% more HIV infections.<sup>9</sup> However, the expansion of ARVs and better efficacy has decreased the pool of infectious people. He therefore posed the question: 'what would happen if more people were being treated?'. To answer, Hirschel drew on Lima and Montaner's scenarios from British Columbia where they looked at various treatment coverage scenarios, and concluded that the program would become cost effective in that province after 2022, if all people with HIV were treated.<sup>10</sup> Hirschel also examined the design of the HPTN 052 study, looking at the effect of treating positive partners in serodiscordant couples immediately, versus waiting until CD4 levels reach within or below the range of 200 and 250 cells. He noted that based on data from the Swiss HIV Cohort Study, the effect of ARVs on transmission look

much less promising when looking only at men who have sex with men (MSM).

## Pre-exposure prophylaxis (PrEP)

Although we still await the results of efficacy trials of PrEP, Lisa Grohskopf presented some 24-month results from the phase II study (CDC 4323) of the biomedical and behavioural safety study of tenofovir at one of the Vienna conference's late-breaker sessions. This study was conducted among 400 men in Atlanta, Boston and San Francisco. Participants were randomised to one of four study arms: two arms comprising immediate daily tenofovir or placebo, and two delayed tenofovir and placebo arms (which started nine-months later). This design was to allow for comparison between the risk behaviours of participants in the immediate and delayed study arms.

Overall, 86% of participants completed all study visits. The conclusion was that tenofovir was safe and well-tolerated at 24 months among HIV-negative men.

*continued on page 45*

## WHAT'S NEXT FOR ARV THERAPY AS PREVENTION?

**The HPTN 052 study of 1763 discordant heterosexual couples in nine countries is due to report in 2013. This will determine the durability of ARVs preventing sexual transmission of HIV.**

The proposed HPTN 065 (also called TLC-Plus) will evaluate the feasibility of an enhanced community-level test, link to care, plus treatment strategy in the United States.

A proposed study will examine HIV incidence among serodiscordant gay male couples in Sydney and Melbourne to determine the impact of viral load on transmission.



# ‘Nothing about us without us’: GLBTI older people and older people living with HIV – prospects, possibilities and self-determination

By Dr Jo Harrison

The role of activism and the importance of self-determination by older people themselves in relation to gay, lesbian, bisexual, transgender and intersex (GLBTI) and HIV-related ageing cannot be underemphasised. As a growing body of evidence builds, and an increasing number of projects develop to address this area of concern, it is vitally important that the voices of older people themselves are central to the changes taking place. Older people need to be in a position of self-determination, so that they are involved as decision makers and recognised as the experts on their own situation and needs. In many respects, this mirrors the approach that

the community took in relation to HIV in Australia. Those directly impacted by the epidemic were integral to the development of solutions to the crisis. HIV/AIDS activists ensured that the government response conquered fear through policy development, research, education and advocacy.

Bill Bowtell has put it:

*‘We got on top of HIV/AIDS in the 1980s because we developed bold, radical and effective new policies that worked. We believed and trusted the community to shape, guide and implement the national HIV response. We did not take much notice of those who said gay men, sex*

*workers, injecting drug users and young people would never change their behaviours.’<sup>1</sup>*

Similarly, fear, scare-mongering and negative stereotyping around ageing can be combated by a community approach which challenges notions that ageing itself is to be dreaded and denied. Older activists and their allies need to be resourced and enabled to lead the way so that outcomes are consumer-driven and culturally appropriate. The training of older people in activist and advocacy skills, including training facilitated by other older people with histories of activism around ageing, is an essential element

of a successful community driven approach to ageing. The involvement of older GLBTI people and people living with HIV as educators in training programs has also proven to be highly effective in projects taking place overseas. The notion of a speakers' bureau, well known in HIV-related education, needs to be made applicable to educative processes in relation to aged-care. In this way, service providers and others will gain an enhanced understanding of the experience of ageing from those with personal expertise.

Doctoral research, which I conducted, investigated activism around the lack of recognition of GLBTI issues in all areas of gerontology (aged-care), including government policy and programs in Australia and the USA. The research revealed a serious lack of attention to concerns related to sexuality and gender identity in the Australian context. In the US context, a history of recognition of GLBTI concerns at all levels of aged-care was apparent and was related to a history of activism. This included an awareness of the significance of ageing issues in relation to HIV.<sup>2</sup>

The deficit in Australian gerontology is reflected in an almost complete lack of mention of GLBTI and HIV-related ageing in aged-care policy, education and training, research priorities, program guidelines and consumer related initiatives, including advocacy. This absence of attention to the special needs of GLBTI older people and their carers and advocates reinforces invisibility and avoids the need to address whether standards of care are culturally appropriate to GLBTI needs and the needs of those living with HIV.

GLBTI consumers and people living with HIV remain almost completely invisible within aged-care services and across the aged-care sector. This invisibility is predominantly due to lifetimes of fear of persecution and discrimination, as well as a current fear of prejudice. Older people describe 'de-gaying' their homes for service providers and even contemplate suicide as an alternative to dependence on

services, particularly residential care. Such fear and invisibility demand culturally competent responses from service providers and government if we are to break the cycle of invisibility and silence.

It is not the case that GLBTI elderly people have to 'come out', to receive sensitive services, or that this is the measure of a 'successful service'. It is vital, however, that services strive to create safe environments and alleviate fear across the aged-care sector. The NSW Department of Health and Aged and Community Services Association NSW/ACT (ACS) Positive Living in Aged Care award was recently given to the 'Safe Space at Our Place' program of Riviera Health, a NSW private sector residential aged-care provider. This demonstrates that such an approach can be incorporated into an aged-care environment to eliminate fear, enhance safety and celebrate diversity.

This approach needs to be replicated across the sector, and the recent federal funding of the ACON cultural awareness in aged-care education pilot project, to be conducted in partnership with ACS, will enhance the process of culturally appropriate education being delivered by GLBTI and HIV organisations themselves.<sup>3</sup>

The discussion paper that I co-authored with the Australian Coalition for Equality (ACE)<sup>4</sup> examines the implications of the legislative removal of same-sex discrimination for GLBTI aged-care and provides some guideposts

for the road that might lie ahead in addressing GLBTI and HIV-related ageing issues. The *Same-Sex Relationships (Equal Treatment in Commonwealth Laws – General Law Reform) Act 2008* amended the *Aged Care Act 1997* so that same-sex couples would be given equity of treatment when assessment for residential care fees and charges takes place. The willingness of ACE to commit to raising ageing issues at the national level is to be commended. The paper has provided a basis for discussions that have taken place with government, including a meeting I attended in February 2010 with the Office of the Minister for Ageing and the Office for an Ageing Australia. This was the first time that a meeting to discuss GLBTI ageing had taken place involving the federal government and followed a period of extensive media coverage of GLBTI ageing issues in both mainstream and gay media, including matters raised with the Senate Inquiry into Suicide in Australia.

The paper also provides an overview of research and related initiatives, the need for education and training, direct service provision, advocacy and policy reform in the context of short, medium and long term options, ranging from adapting the paperwork and forms used by Aged Care Assessment Teams to the formal recognition of GLBTI older people as a special needs group

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and a National GLBTI Aged Care Plan, which would include targeted funding programs. It includes an overview of developments taking place across Australia that relate to GLBTI ageing, including the research work of the Matrix Guild in Victoria and the GLBTI Retirement Association in WA, the Val's Café Gay and Lesbian Health Victoria (GLHV) aged-care audit and training, the work of Rainbow Visions in the Hunter region, Riviera Health's initiatives with staff, the work of Lesbian and Gay Solidarity and long term ageing activists Kendall Lovett and Mannie de Saxe, the work of the Queensland Association for Healthy Communities and its Ageing Action Group, the ageing work of the National LGBT Health Alliance and the launch of the Alzheimer's Australia paper *Dementia: Lesbians and Gay Men* by Michael Kirby at an ACON, ACS and Alzheimer's Australia event, and similar events around Australia.

The issues canvassed in the paper are particularly pertinent given the impending federal control of all aged-care matters and the need to ensure protection from discrimination to all consumers of aged-care services. As Senthoran Raj points out, federal anti-discrimination legislation in relation to sexuality and gender identity is urgently needed so that consumers of aged-care services are protected from discrimination and persecution in a sector which will be coming under federal control.<sup>5</sup> That the Discussion Paper of the current Productivity Commission Inquiry into Aged-care refers to 'gays and lesbians' in relation to 'other groups with special needs' is evidence that the issue warrants, and is receiving, national attention.

As GLBTI and HIV-related ageing receives greater prominence at a national level, it will be imperative that such change takes place in the context of the empowerment of older people themselves to speak on their own behalf and advocate for their own

rights and entitlements. Without this process, the unfolding interest and awareness around GLBTI ageing will lack the bedrock provided by the voice of consumers that has driven gains in other areas of aged rights advocacy in Australia. Those of us yet to experience life as GLBTI older people, or older people living with HIV, will also lack the insight that could be gained from fulfilling our roles as facilitators and enablers of self-determination.

One of the messages that was emphasised to me by experts and activists in the US and in Australia was the well-known social movement catch-phrase 'nothing about us without us'. The work of driving change needs to be done by GLBTI and HIV organisations, and by empowered older people. The 'nothing about us without us' approach could be reflected in the way that older people themselves are part of delivering, guiding and enhancing the success of projects that seek to educate and drive change.

The GLBTI response to HIV/AIDS was not to rush to develop residential care facilities as a quick fix, and nor should it be to ageing. Those who take action around ageing have much to learn from the community response to HIV. As Christian Hart put it:

*'We realized the importance of taking care of our own. We expressed courage in the face of death. We achieved success in creating a positive sense of identity for those living with HIV. We created new organizations, movements, and political armies.'*<sup>6</sup>

In similar fashion, as a community we will challenge negative stereotypes and stigma surrounding the process of ageing. We will continue to seek and attain the support of governments that have yet to include us in policy or programs in aged-care. Our response to ageing will be unique, admirable, somewhat shameless and inspiring to others. This process will continue to take place in partnership with those across the aged-care sector who possess

great foresight. Most importantly, the voices of our own elders must be loudly heard at the forefront of change so that diversity can be celebrated and fear of discrimination eradicated.

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# HAART and mind: HIV-cognitive impairment, antiretroviral therapy and ageing

By Prof Bruce J Brew

It was originally believed that the introduction of highly active antiretroviral therapy (HAART) would see the end of dementia and less severe forms of cognitive impairment in people living with HIV. Unfortunately, this is not the case. HIV still leads to cognitive impairment (also known as 'HIV-associated neurocognitive disorders', or HAND) in some patients, despite HAART.

When early studies showed that in fact there had been no significant change in the frequency of HAND, most considered this was probably related to a 'legacy' effect – in other words, patients had been impaired and then started HAART but there was a degree of fixed or irreversible damage that remained.

Further studies have cast doubt on this as the major explanation. It may be true in some patients, but it cannot be the main reason for the presence of HAND in HAART-treated patients as cognitive impairment has been shown to *develop de novo* in approximately 25% of patients who were already taking HAART. Some clinicians have dismissed this as merely reflecting inadequate viral suppression in the blood. This is *not* the case; the development of HAND has been repeatedly shown to occur in patients who *are* virally suppressed.

What has changed with the introduction of HAART is the severity of HAND. Fortunately, the severe form, namely dementia, is now very

uncommon, while milder forms are frequent. This is reassuring, but it provides little comfort. Milder degrees of HAND are still associated with job difficulties and sometimes job loss – not to mention problems with medication adherence. Thus there is a paradox: potent antiretroviral drugs work for severe cases of HAND, but do not seem to be effective against mild impairment.

What is the explanation? Presently, the answer is unknown. Nonetheless, there are several possibilities. Patients with mild HAND symptoms may delay seeking medical attention in the belief that the mild symptoms they

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experience are not of any consequence. By the time medical intervention occurs, however, there may already be a sizeable degree of accumulated fixed damage. This stands in contradistinction to more severe disease, which develops more quickly and where medical intervention can be delivered more acutely.

Other patients may develop HAND as a result of inadequate brain levels of HAART, while some may develop impairment as a consequence of HAART CNS toxicity, though the evidence for this is still tenuous.

Perhaps the most important potential explanation is the possibility that some patients develop HAND as a consequence of accelerated ageing. Certainly, there are increasing numbers of people becoming infected at an older age, as well as patients growing old with HIV – including cases where people have been living with the virus for over two decades.

Ageing can impact the brain in two ways: the ageing process *per se* can affect cognition, and along with ageing also comes the diseases of ageing – in relation to the brain these are disorders such as Alzheimer disease (AD).

HIV seems to be able to both accelerate the ageing process and facilitate the development of some of the diseases of ageing.

What is the evidence for these processes as they pertain to the brain? Recent studies of the blood flow to the brain have shown that HIV-positive

subjects, who are otherwise well, have brain blood flow rates that are the equivalent of people 15 years older. Furthermore, post mortem studies have shown that HIV infected brains have raised concentrations of tau, a protein associated with ageing, that again matches levels usually found in much older people. Currently, it is not known how HIV does this.

HIV also seems to be able to accelerate degenerative brain diseases. Among these is AD, or at least something akin to it. There are many lines of evidence: common risk factors (insulin resistance, midlife raised cholesterol, genetic susceptibility status (APOE), an elevated subpopulation of white cells (CD69 monocytes), abnormal cerebrospinal fluid levels of AD biomarkers in HIV, post mortem evidence of the some of the hallmarks of AD (amyloid plaques as well as neurofibrillary tangles), an overlapping anatomic substrate (the ‘memory’ part of the brain, the hippocampus), and common causal pathways (inflammation, and disturbed cellular waste disposal systems (ubiquitin-proteosomal function, inhibition of autophagy).

HIV also causes a build up of amyloid, the sticky protein that is linked to brain disease in AD. Furthermore, HIV is associated with other degenerative brain diseases, such as Parkinson’s and motor neurone disease. How HIV ‘assists’ in the development of these conditions is still unclear.

Thus the downside to the life-prolonging effects of HAART is that ageing and its associated effects appear to be accelerated, especially in relation to the brain. It is now up to researchers – with the help of the HIV positive community – to better understand this in order to improve the cognitive health of people living with HIV. It is a tall order. But so too was a treatment for HIV when it was first discussed more than 25 years ago. And look how far we have come.

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**Professor Bruce Brew MBBS MD FRACP is Head of Neurology in the Department of Neurology at St Vincent’s Hospital in Sydney. He has over 20 years experience in clinical and basic science aspects of the neurological complications of HIV disease and has conducted numerous trials on HIV dementia and neuropathy.**

Professor Bruce Brew, Paul Kidd (National Association of People Living With HIV/Victorian AIDS Council) and Dr Edwina Wright (Alfred Hospital/Burnet Institute) discussed issues relating to HIV and ageing recently with Radio National’s Natasha Mitchell, as part of an episode of the ABC science program *All in the Mind*. Links to audio from this broadcast are available in the digital edition of *HIV Australia* at [www.afao.org.au](http://www.afao.org.au)

It is now up to researchers – with the help of the HIV-positive community – to better understand this in order to improve the cognitive health of people living with HIV.



# Ageing and HIV – the story unfolds ...

By Ross Duffin

Since around 2006, the story about the impact of long term living with HIV on the ageing process has gradually begun to be told. There's a lot more to be known but it is clear that something is going on: the ageing process is accelerated in people with HIV.

This story hasn't yet been communicated to people living with HIV – partly because of uncertainty, partly because there's a lot more to learn. The time has come to start communicating because the acceleration of the ageing

process for people with HIV has huge implications. It may be the case that looking after organ systems that are susceptible to accelerated ageing becomes as important as HIV treatments in determining how well you are as you get older.

Ageing was never a discussion we thought we'd have in relation to living with HIV. Even without the news about accelerated ageing, the changing age profile of the HIV population is a big story in itself. In 1996, when

combination treatments first became available, less than 15% of people living with HIV were aged over 50. Now, over one in three HIV-positive people is over 50, and by the end of this decade over 50% will be. We are replacing the epidemic in people under 40 (let's not forget this), and we have, by and large, a relatively new older epidemic – an epidemic that will be increasingly affected by accelerated ageing.

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There has been a much longer discussion about ageing in the gay and lesbian community. When I first came out in the 1970s, openly gay men seemed very young. It was, after all, a young movement. Ageing was either something we didn't talk about, or was frowned on as a place we didn't want to get to. By the early 1980s, the gay movement had expanded and we'd begun to talk about ageing a little bit. The arrival of HIV stopped that conversation. When I found out I was HIV-positive I didn't expect to see the turn of the century. Who now cared about ageing?

The 90s was a decade of two halves. The first half was dominated by AIDS – a disappearing four letter word in this country. “Sydney” won the Olympics. In 1996, the arrival of combination therapy was announced; we wondered how long it would last – but we thought we'd get to the Olympics and a new century. We went from living life in the fast lane, to getting older and wondering how long these treatments would keep us alive. We now know – they've kept most of us alive ...

From the late 90s, the broader gay community was less and less defined by HIV – and outside HIV-positive

circles, discussions about lesbian and gay male ageing were more common. Lesbians and gay men no longer all seemed young. After all, it was almost thirty years since the beginning of the lesbian and gay movement in Australia.

For gay men with HIV the world looked different. By 1996 when effective treatments arrived, there were very few older people with HIV – effectively a generation of gay men had already died from AIDS. There was no HIV and ageing story because there were very few older people with HIV.

#### And now

Now, 14 years or so later, we do have an older generation of people with HIV.

There have been attempts to collapse HIV ageing and gay and lesbian ageing into one issue. Of course there are overlaps but accelerated ageing makes 'HIV ageing' quite distinct – and over 20% of people living with HIV are not gay. Because appropriate care for ageing people with HIV is characterised as a health issue, strategies to address aged-care issues for people with HIV are already underway. The issues of gay and lesbian ageing are still frequently not addressed in an aged-care sector that often tries to tell us that sexual

identity is not an issue once you are old enough for aged-care. A lot of the next generation of lesbians and gay men are not prepared to be silent about their sexual identity. It would be useful for addressing HIV ageing if the ageing issues relevant to those groups most affected by HIV were addressed in parallel – and that people with HIV were not expected to be the battering rams of social change in their aged-care service.

There are a number of important reasons why we need to address HIV and accelerated ageing before we are overwhelmed by its impact. There is a common belief that we already have a large population of people with HIV in their 50s and the services are coping fine. This is not so. At the moment most HIV-positive people in Australia experiencing co-morbidities (conditions that occur commonly when you have long term HIV infections), are in their 50s and attempting to manage conditions that usually don't occur frequently until people are in their 70s. These co-morbidities are mostly progressive. Chances are we'll face much more serious illness by the time we make it to our late 50s.

It used to be you went to your HIV doctor for a 15 minute consultation on your HIV treatments. It's often the case now if you are over fifty that the HIV treatments discussion has become routine and can be dealt with quickly. But for those of us with a number of co-morbidities, it seems like we never get enough time with our doctors – and the amount we are expecting our doctors to deal with and know about is ever increasing. HIV doctors are now expected to not only specialise in treatments and side-effects, but also to have somehow morphed into quasi-gerontologists specialising in HIV.

If Medicare and the health system had trouble adapting to 'HIV specialist GPs' it will have even more trouble with 'HIV specialist GPs and gerontologists'.

At the moment most HIV-positive people in Australia experiencing co-morbidities ... are in their 50s and attempting to manage conditions that usually don't occur frequently until people are in their 70s. These co-morbidities are mostly progressive. Chances are we'll face much more serious illness by the time we make it to our late fifties.

At the moment there are over 1000 new diagnoses of HIV infection every year in Australia. The death rate of people with HIV from all causes is much less – probably under 300 per year. Treatments have kept us alive and our survival means that there are ever increasing numbers of people living with HIV – about double the number there were in 1996, when improved treatments arrived. Although some of that increase can be explained by rising infection rates (especially in people over 40), it is by and large due to a generation of people now living close to a normal life expectancy.

### The future

It is anticipated that over the next decade the death rate of people with HIV will gradually approach the infection rate – and be even higher than it was in the peak death years from 1990 to 1996. But unlike the 1990s, this will not be an epidemic of deaths among people in their 20s, 30s and 40s – it will be mainly deaths in people over 50. The issue caused by accelerated ageing is the increased number and severity of co-morbidities experienced by HIV-positive people. People living with HIV are more prone to a number of serious illnesses, periods of hospitalisation become more likely, and the whole process becomes more expensive to manage.

Case-mix funding is on the way. It is sometimes the case that conditions perceived as ‘expensive’ do badly under case-mix, and indeed it is almost certain the medical costs of looking after older people with HIV will be underestimated because we don’t yet have the data.

The other issue that will be affected by the huge increase in people with HIV over 50 is appropriate accommodation and aged-care services. The discussion is often dominated by aged-care (as it is the thing most feared by my peers) – but there’s a range of strategies and services designed to keep people

in their homes or other appropriate accommodation. The main issue is whether there is the volume of services to cope with what’s coming.

There is also a major issue with being able to continue to work, or the need to go to less-demanding jobs. Many people who have long term HIV infection may face increasing frailty as early as in their late 40s (depending on when they first became HIV-positive). Reduced work capacity caused by people with frailty due to chronic ill-health has not been recognised by policy-makers tweaking DSP and age pension rules. Inflexible eligibility criteria for DSP can result in frail HIV-positive people struggling on Newstart when they should be on pension. This issue will be compounded as the retirement age and minimum age for access to age pension increases.

### What it all means for this cranky old queer ...

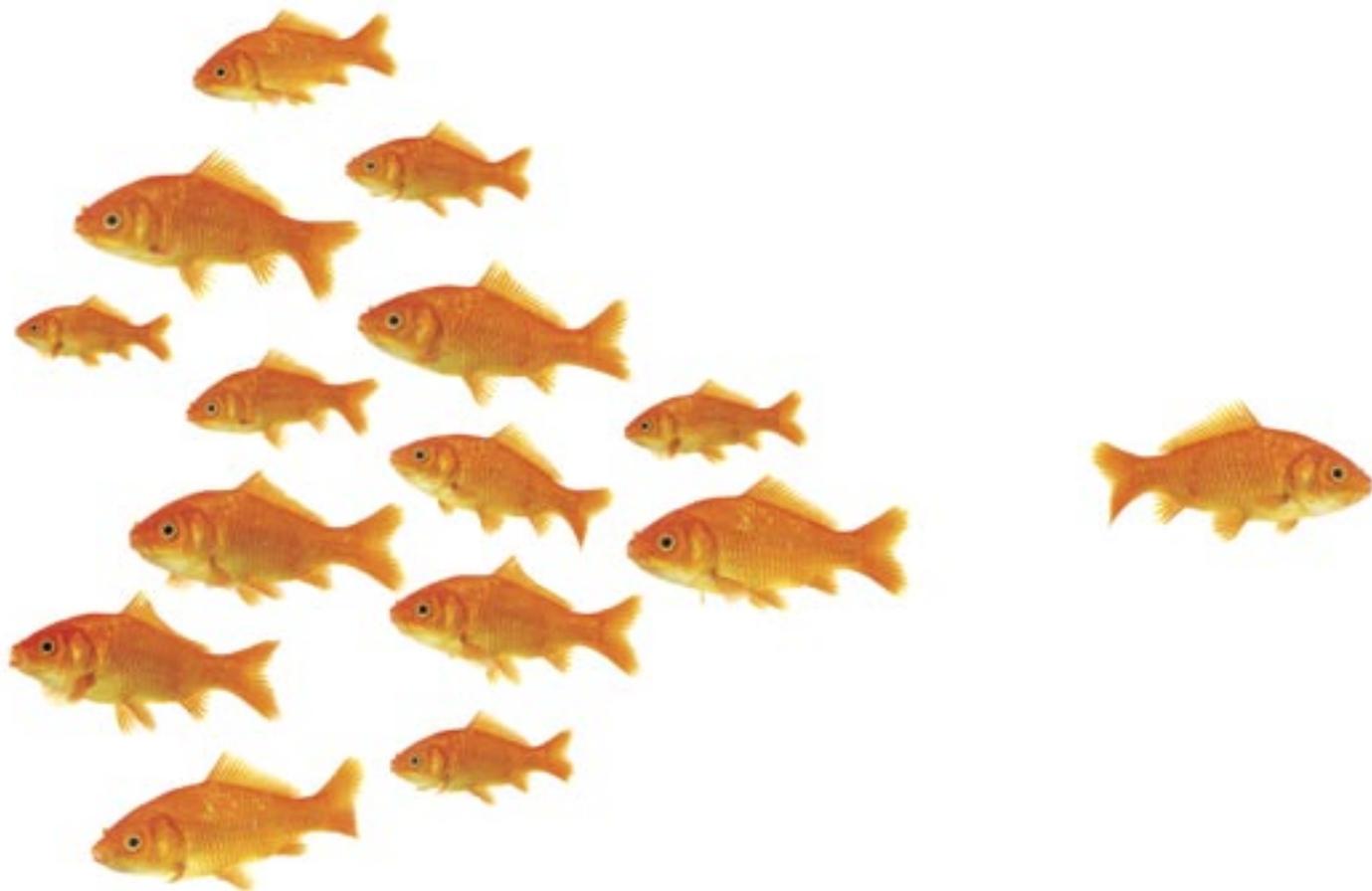
For me it’s not dying I fear – it’s getting there. This was exemplified for me this year when I had a stroke, which has played havoc with my short term memory – my ability to remember words, people’s names, and memories of what happened in the last decade. It wasn’t all bad – it seems to have zapped

some of my tendency for depression. If I am to face a number of years like this then it’s not exactly a prospect that I look forward to. I retired from HIV-related work in a vain attempt to find a place where instead of living inside HIV, I could live beside HIV. But for the first generation of people with HIV it seems there is no escape.

For the next generation the information on ageing means that people living with HIV will have to tune into HIV more often – and learn about preventative health for their futures. For me, I’m sort of bizarrely happy being a cranky old queer (COQ) – annoyed that once again HIV has bitten us and it seems like there is a third phase of HIV illness that has yet to be fully understood and explained.

**Ross Duffin has been involved in the HIV sector for over 25 years. He has been retired for a number of years and suffers from accelerated ageing and crankiness.**

The issue caused by accelerated ageing is the increased number and severity of co-morbidities experienced by HIV-positive people. People living with HIV are more prone to a number of serious illnesses, periods of hospitalisation become more likely, and the whole process becomes more expensive to manage.



# A changing epidemic, a changing workforce: implications of HIV and ageing for general practice

By **Christy Newman, John de Wit, Michael Kidd, Robert Reynolds, Peter Canavan and Susan Kippax**

'HIV and ageing' affects general practice in two fundamental ways. The first is that as people with HIV get older their health needs change – affecting the kind of primary care they require. The second is that the general practice workforce which supports people with HIV in Australia is itself getting older, with a considerable number of doctors who have been providing HIV primary care for many years now heading toward retirement.

A concern that recurs in policy debates on HIV clinical care in Australia is that the number of general practitioners (GPs) training as HIV antiretroviral (s100) prescribers and able to provide

medical care and advice for the growing number of people living with HIV may be insufficient to replace those retiring, reducing their working hours or changing their roles.

To explore these issues, the National Centre in HIV Social Research at The University of New South Wales is leading a three-year study funded by the National Health and Medical Research Council. The study will provide evidence about why and how general practitioners pursue a special interest in HIV medicine. The research is guided by representatives from Flinders University, the National Association of People Living with

HIV/AIDS, the Australasian Society for HIV Medicine, the Australian Federation of AIDS Organisations and the Royal Australian College of General Practitioners.

## **Ageing of the patient cohort**

The first stage of the research involved interviewing 24 key informants in senior policy, advocacy and education roles in all states and territories, to identify the primary issues affecting the HIV general practice workforce in Australia. Participants included 17 men and seven women from a range of professional backgrounds including medicine, allied health, public service and community advocacy.

Five participants self-disclosed as HIV-positive.

A central observation made by these interviewees was that HIV care needs are likely to change considerably over the coming years as the current cohort of people living with HIV gets older, and given that the age at which Australians are being diagnosed with HIV is rising. In addition, the potential 'accelerated ageing' of people living with HIV was identified as a concern in terms of bringing forward in time many of the health issues associated with ageing.

In combination, these issues were described as posing serious challenges to our nation's capacity to continue to provide quality primary care for HIV-positive people into the future. The focus therefore becomes how this perceived shift in the nature of HIV care will impact on whether GPs and other members of general practice teams decide to commence or continue working in this field.

### **Workforce attrition and attraction**

This brings us to the second area in which 'ageing' is seen to affect the general practice workforce in Australia, including HIV antiretroviral (s100) prescriber GPs. As with many other professional groups in Australia and in other developed nations, many Australian GPs are planning to retire within the next decade, and many others plan to reduce their clinic hours or change their area of work. This has particular implications for the provision of HIV care because of the significant role that many GPs have played in the provision of HIV care in Australia since the start of the epidemic.

Our key informant interviews suggested that 'ageing' issues are becoming central to the recruitment and support needs of the HIV general practice workforce in Australia. The next phase of our study comprises interviews with clinicians to explore this and related issues. We are hoping

to interview current HIV s100 prescribers, GPs and other clinicians who once worked in HIV but have retired or moved into new areas, other members of general practice teams who currently provide HIV care, and GP registrars with an interest in HIV.

The *Sixth National HIV Strategy* (2010–2013) recognises these issues, noting 'recruitment and retention difficulties for Section 100 GP prescribers and clinicians with an interest in HIV'. Addressing these factors will be challenging given the national health workforce shortage and the growing pressures on both specialist and primary care funding in Australia. Our study will provide critical evidence for how best to support GPs to continue to provide ongoing care for people living with HIV in different parts of Australia. Of particular interest will be the experiences of GPs who have been treating HIV-positive patients for various lengths of time, with different HIV caseloads and in both urban and regional settings.

### **A changing epidemic; a changing workforce**

One issue that may be of interest here is the belief held by some people that many of the GPs who have worked in the field since the 1980s have done so because of a sense of socio-political duty to the communities most affected by HIV, notably that of gay men. It may be that younger or more recently trained GPs will have different motivations, perhaps because many did not directly

experience the emotional and political intensity of the first decade of the epidemic, or perhaps because the politics of sexual identity have also been changing since that time.

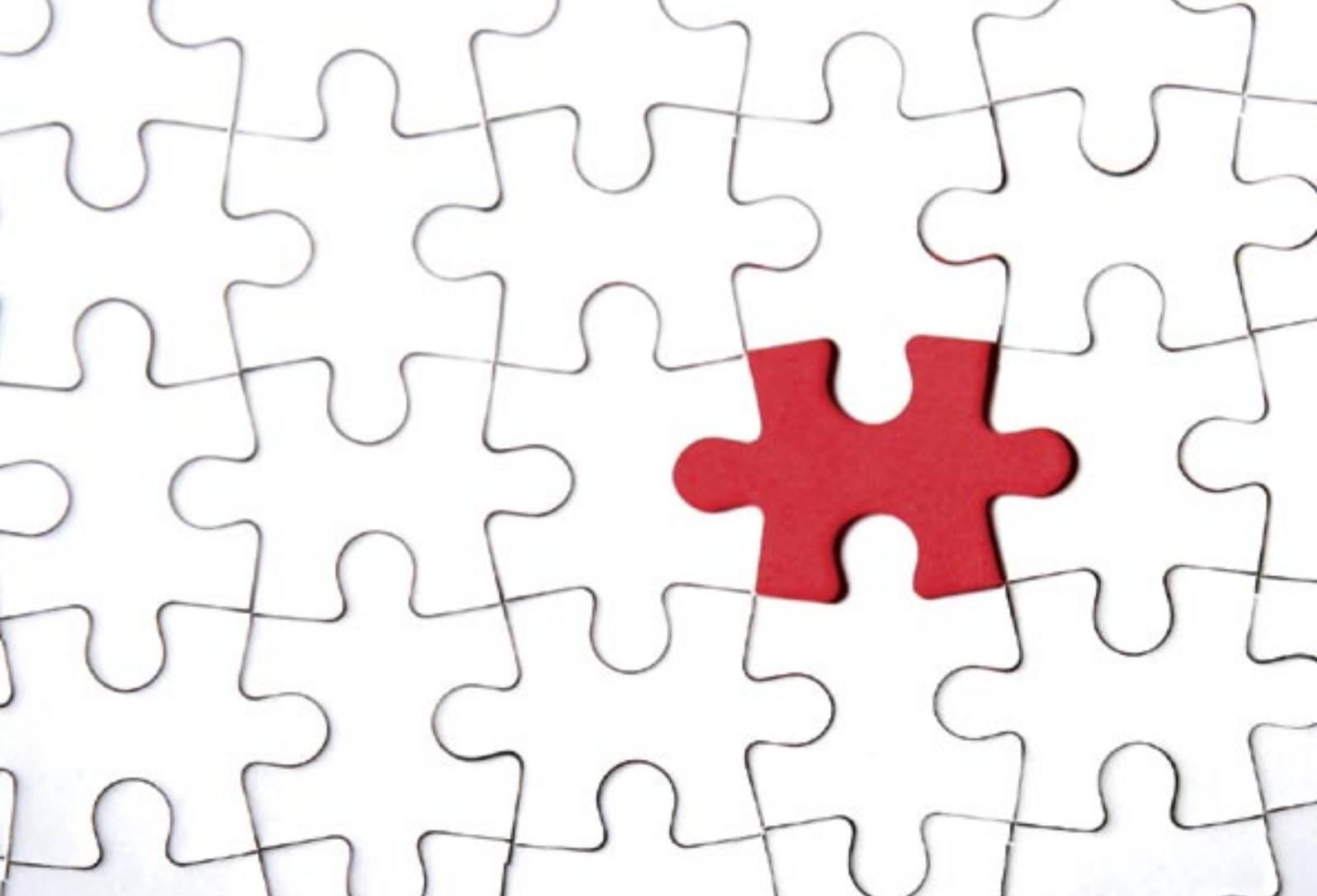
This study represents a unique collaboration between HIV social researchers, general practice researchers, partner organisations from the HIV and general practice sectors and general practitioners. In particular, including a consumer advocate on our core research team demonstrates the partnership that has been formed across our interdisciplinary team in order to genuinely represent the different voices of research, advocacy, policy and clinical practice.

This partnership will ensure that the outcomes of this study have a direct impact on our nation's policy and advocacy response to HIV, through the committed involvement of the peak organisations that have responsibility for representing PLHIV and the members of the general practice workforce who provide HIV care in Australia.

**For more information or to take part in a clinician interview, please contact Christy Newman at [c.newman@unsw.edu.au](mailto:c.newman@unsw.edu.au)**

**Dr Christy Newman is a Senior Research Fellow at the National Centre in HIV Social Research at The University of New South Wales and the primary researcher on the HIV General Practice Workforce Project.**

The focus therefore becomes how this perceived shift in the nature of HIV care will impact on whether GPs and other members of general practice teams decide to commence or continue working in this field.



# ART imitates life: the puzzle of HIV, ageing and antiretroviral treatment

By Prof Jennifer Hoy and Dr Olga Vujovic

The benefits of antiretroviral therapy in prevention of progression of HIV to AIDS – and thereby in improving survival of people living with HIV – have been known for 15 years.

The SMART study, which compared continuous antiretroviral treatment (ART) keeping the viral load as low as possible with intermittent treatment used only when the CD4 cell count dropped below 250 cells, was pivotal in enhancing understanding of the effects of adherence to ART. It showed that ART not only prevents HIV-related opportunistic infections, but also many non-AIDS complications such as heart disease, cancer, kidney and liver disease.

It also showed that these complications are more common at lower CD4 cell counts.<sup>1</sup> We learnt from this study that is NOT smart to stop ART.

The unexpected findings from the SMART study also influenced many treatment guidelines, with some extrapolating the findings to mean that ART should be commenced as soon as HIV infection is diagnosed. Such guidelines are contentious; the clinical trial evidence for starting treatment below 350 CD4 cells is clear but there is a lack of good quality data to support the commencement of treatment at CD4 cell counts above 500 cells. The benefits of preventing the AIDS-

related diseases and HIV-related non-AIDS complications have not been compared with the risks of ART, which include immediate adverse effects, risk of development of resistance and limitation of future treatment options, as well as long term toxicity for people with high CD4 cell counts – a risk especially important for older HIV-positive people.

## **An ageing cohort**

In the last two years, approximately 30% of all new HIV diagnoses in Australia have occurred in individuals aged 50 years and over, and it is anticipated that 50% of those living with HIV in 2015 will be over the age

of 50 years.<sup>2</sup> In Victoria, those over the age of 50 are seven times more likely to be diagnosed with HIV when their CD4 cell count is less than 200 cells or when they have an AIDS illness.<sup>3</sup> Studies have reported a 50% increased risk of clinical disease progression and poorer survival in those aged over 50, despite initiation of combination ART.<sup>4</sup> This greater prevalence of co-morbid conditions normally associated with ageing is largely responsible for the greater mortality observed in the older HIV-positive person.

Although the recommendations for when to initiate ART do not differ for older adults with HIV infection, the choice of ART needs to be individualised with respect to pre-existing disease. The potential impacts of the recent trend towards earlier antiretroviral treatment given an older HIV-positive population require careful consideration.

Management of HIV is complicated by the presence of co-morbidities such as hypertension, metabolic disorders such as diabetes, insulin resistance and hyperlipidemia, liver disease, renal impairment, bone disease, neurocognitive impairment and cancer. Co-morbidities already experienced by older HIV-positive people need to be taken into account as potential short- and long-term toxicity may have great impact on the older HIV-positive individual.

The example of cardiovascular disease underscores the complexity of the relationship between HIV infection, ageing and ART. Observational studies and randomised trials have clearly reported an increased risk of cardiovascular disease among people with HIV – a risk that is greater for older patients and those with lower CD4 cell counts. But observational studies have also reported increased rates of myocardial infarction (heart attack) with specific antiretroviral drugs. Protease inhibitor containing regimens were the first to be shown to be associated with increased myocardial

infarction, with the relative risk per additional year of protease inhibitor greater than the risk per additional year of age.<sup>5</sup> The risk varies according to different protease inhibitors, and the mechanism by which these drugs cause increased cardiovascular disease is thought to be the changes in blood cholesterol and triglycerides caused by these drugs.<sup>6</sup> The current use of abacavir has also been associated with an increased risk of myocardial infarction, although the causative mechanism is not yet understood.<sup>7</sup>

Older individuals initiating ART are less likely to restore their immune system. Despite successful treatment with ART and achieving sustained virological suppression, people over the age of 50 years have slower rates of CD4 cell recovery and smaller CD4 cell increases. The average monthly CD4 cell increase for the first six months after initiation of ART is significantly lower for older adults (37 cells/month versus 42 cells/month in those less than 50 years), and the less robust and delayed CD4 cell recovery was maintained from 6 to 12 months.<sup>8</sup> These differences may persist for at least five years. Other studies have shown no differences in the CD4 cell increases between older and younger patients.<sup>9</sup>

On a more positive note, it has been observed that older HIV-positive people are more likely to achieve complete virological suppression and achieve virological suppression faster

in response to ART. This was observed with protease inhibitor based ART. Older individuals are also less likely to develop virological breakthrough or treatment failure, which is most likely related to better adherence to treatment.<sup>10,11</sup>

The clinical consequences of incomplete immune recovery include the serious non-AIDS illnesses (greater rates of cardiovascular disease, liver disease, kidney disease, bone disease and fractures, neurocognitive impairment, cancer) in addition to HIV-related opportunistic infections.

Antiretroviral treatment tolerability may decrease with age. A study from a large American healthcare provider has shown that older HIV-positive people have greater toxicity to ART compared to their younger counterparts. Older patients (over 50 years of age) were more likely to develop significant laboratory abnormalities after starting ART, including metabolic (increased glucose, cholesterol, and triglycerides), hematologic (white cell count and haemoglobin) and renal (creatinine) dysfunction.<sup>12</sup> Another study made the observation that older patients have higher levels of blood glucose, cholesterol, triglycerides and creatinine prior to commencing ART, so that similar magnitudes of increase in these metabolic markers in the old and the young places the older HIV-positive

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Older individuals initiating ART are less likely to restore their immune system. Despite successful treatment with ART and achieving sustained virological suppression, people over the age of 50 years have slower rates of CD4 cell recovery and smaller CD4 cell increases.

person at greater risk of diabetes, metabolic syndrome, hypertension, hyperlipidemia and cardiovascular disease.<sup>13</sup>

The ART drugs and medication used to treat other co-morbidities may have drug-drug interactions, which complicate their use. The risks of unrecognised drug interactions include HIV treatment failure and development of resistance if ART drug concentrations are lowered by other medication, OR increased adverse effects or overlapping toxicity of the ART drugs and the other medication. Older individuals are likely to be on multiple medications for co-morbidities such as hypertension, high cholesterol and diabetes, and polypharmacy may be difficult to manage. Dose adjustments may be required as new medications are started, with adjustments to the number of pills taken and frequency of dosing each day – some after meals, some before meals, some before sleep. This makes adherence complicated. However, although the likelihood of poor adherence to treatment generally increases with increasing pill burden and number of doses required each day, studies have shown that adherence is superior in those aged over 50 years.<sup>14</sup>

The latest hypotheses generated to explain the worse outcome for people with HIV infection on ART compared with the general population of the same age suggest that despite HIV viral load levels below 50 copies/ml on ART, there is sufficient low level viral replication to induce persistent immune activation. This persistent immune activation leads to 'immune exhaustion' and the immune decline similar to that seen in healthy ageing. This immune senescence means there is a reduction in immune surveillance and increased disease, e.g. cancer, infections.

### Monitoring of side-effects essential

The routine monitoring of older HIV-positive people on ART involves

more than monitoring HIV viral load and CD4 cell counts – it requires consideration of the long term side effects of ART that affect cardiovascular risk, metabolic disease and diabetes, renal disease and bone health, and modifying ART in response to these co-morbidities. HIV management in older patients is complicated by the presence of co-morbidities; both HIV and ART itself may contribute to the co-morbidities, which themselves have an important bearing on the selection of ART regimen.

In order to achieve the best possible health outcomes for older people living with HIV, continual assessment and active interventions are required for HIV therapy and co-morbid conditions. In the current era, co-morbid conditions are responsible for an increasing burden of illness.

A robust approach includes patient education, prevention strategies (e.g. smoking cessation), in addition to aggressive management of established disease such as hypertension and hyperlipidaemia. A strong partnership approach between HIV-treating doctors and primary health care providers, underpinned by skilled nursing interventions, has been demonstrated to be an effective model of chronic disease management in other arenas and thus should be similarly effective for management of chronic disease in the context of HIV infection.

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# Hearing our stories: community views on ageing and HIV

By Russell Westacott

Over the last couple of years ACON has placed GLBT ageing issues on the agenda of its three-year strategic plan. In 2006/7 ACON released the *Ageing Disgracefully* report, available for download on the ACON website ([www.acon.org](http://www.acon.org)).

To better understand the psycho-social issues of HIV and ageing, ACON has held three community forums on ageing and HIV over the last three years. The events were attended by around 30 people living with HIV.

While the forums were open to both men and women – straight and gay – only gay men attended; most of the participants were in their late 40s, 50s and 60s.

The forums were offered for the purpose of hearing the stories of people living with HIV who now find themselves growing older – to gain insight into the lived experience of being positive and ageing. The participants discussed a range of issues that were important to them and the discussions were

moderated by an external facilitator. In no way does this article cover all of the territory that our participants discussed, rather, I have focused on six key themes that emerged out of the forums.

## Rapid progression of ageing

We know from a range of different data that HIV can bring about the early onset of a range of chronic health issues often associated with ageing, including diabetes, cancers and osteoporosis.

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In our group discussions, several participants talked about the speed by which they noticed their ageing process increase. They mentioned things like loss of energy, changes to body shape, a general sense of physical decline and changes in mood. While these issues are probably commonplace for most people who experience ageing, here these stories came from a demographic not typically considered 'old'.

It should be noted that some participants accepted these changes as manageable. Some noted the challenges they faced regarding these issues, but in doing so they expressed a desire to confront them by trying to understand how to minimise the impact on their bodies. These men were eager to educate themselves as best they could.

### **Mental health and anxiety**

Many participants talked about a range of mental health issues they were currently living with. The discussions made it clear that many of these men experienced anxiety around growing older and ageing at increased rate. For some this was happening in the absence of a partner, family or network of close friends, which contributed to their anxiety.

It was not only physical and emotional changes these men were confronted with – for many it was about the life changes they had commenced years earlier. Many of these men had given up careers and more secure employment back when the 'Grim Reaper' was telling them they were about to die.

Our participants told us stories about moving into less stressful careers for the sake of their health and wellbeing, sacrificing long term employment prospects and financial security in the process. Several participants highlighted fears about how they will get by once they reach a point when they can no longer work.

For many, superannuation was cashed in and spent years earlier. The money some of these people make today will not be enough to cover their retirement costs, especially as these costs may be more expensive and come at a younger age than is common.

Linked to this uncertainty – this loss of control in terms of life planning – some participants highlighted a sense of depression. Depression was a common theme that was raised in all the forums. However, it is important to note that some participants challenged this notion, describing the benefits of their sea change and the fact that they worked hard to make their early life-changing scenarios a success, maximising the benefits of these life changes.

Another prominent theme that emerged was dementia. Many were aware that dementia is sometimes linked to advanced stages of HIV disease progression, particularly among those who have been living longer-term with HIV. The burden of knowing that dementia may cause cognitive impairment linked to HIV, and may occur earlier in life, caused some participants to express anxiety.

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### **Self-esteem issues**

Self-esteem was a common issue raised in all the discussions. Participants spoke about grief and loss around losing friends – either to the epidemic or loosing touch because of growing old. This grief was compounded by people's emotions around changes in their health and body shape – changes that often occurred more quickly than usual. Some expressed real challenges with their own personal perspective and a genuine loss of self-confidence because of this.

### **Resiliency**

Interestingly, in contrast to the issues of self-esteem raised above, other men in the groups expressed a real sense of resiliency, saying they had found their own coping mechanisms despite the multiple challenges they faced over the years. They seemed to draw upon not only their own personal resources, but were able to identify appropriate support services at critical junctions throughout their experience of living with HIV. These people also gained valuable insight from hearing about the lived experience of others, highlighting the ongoing need for facilitated support structures that bring together people to share experiences about living with HIV.

### **Mainstream services**

Another common theme participants raised was the lack of aged-care facilities for the gay, lesbian, bisexual and transgender (GLBT) community more broadly. With the absence of mainstream aged-care models, many people living with HIV who took part in the ACON forums expressed fears about their vulnerability regarding the possibility of needing to move to an aged-care facility some time in the future.

If a GLBT-friendly aged-care facility is not available then what implications might there be for people living with HIV – in this case gay men living with HIV – who are growing older and

in need of specialised services? How would an ageing HIV-positive person be treated in a mainstream aged-care facility – not only by staff but by others who were utilising the service?

## Legal issues

Throughout all of the ACON forums, participants spoke about a range of legal and financial issues. Some I have already touched on, but I would like to expand further on some of these here.

As we know, until recently same-sex partners have had limited recognition under Commonwealth law, particularly in the event of the death of a partner. This issue was of particular concern to the men in our sample, given some had already experienced this, or faced the real possibility of this event occurring in the future. Many expressed feeling vulnerable and unsure of their rights in the event of the death of their partner. Some highlighted recent experiences of not being able to access their partner's superannuation, as well as stories about joint possessions being taken by relatives of the deceased. Many were relieved to learn of recent changes in Commonwealth law that now positively impacted on their own personal situation.

Some participants highlighted the issue of being single and growing older without family or friendship networks in place. These people expressed concerns about their own situations, mentioning issues such as guardianship and who to appoint in the event of declining health. In these scenarios the Public Guardianship offers some provision, however for some people felt this was not a suitable outcome – their desire was for support on a more intimate level.

## ACON's responses to the issues

After years of uncertainty around living with HIV, and now the real possibility that for many of the people we spoke to living with HIV means both growing older and doing so earlier, there are real challenges for service providers.

Providers like ACON need to offer a range of relevant psychological and social support services that connect with the myriad of lived experience to offer an ageing HIV-positive population in Australia access to an easy as possible path to travel.

Once a month ACON convenes a monthly work-group which focuses mainly on policy and research issues and has recently started dialogue with a range of potential aged-care service providers. ACON continues to hold GLBT ageing forums and events, including events offered as part of Senior's Week. These events attract a diverse cross-section of people growing older in the GLBT community.

Specifically, on the issue of people living with HIV who are also ageing ACON offers a range of services:

- Counselling for people experiencing a range of issues associated with living with HIV and growing older
- Healthy Life Plus gym and wellness program
- Community Support Network offering home and community support
- ACON has developed with AFAO and NAPWA a printed and web-based information booklet for people living with HIV who are growing older. The resource is titled *Ahead of Time: A practical guide to growing older with HIV*<sup>1</sup>
- ACON's Positive Living Centre and Luncheon Club services also caters to well over 1,000 registered clients between them, many of whom are experiencing growing older with HIV and these services ensure this client segment have a social support network to draw upon.

ACON also recently received funding from the Commonwealth Government to collaborate with the Aged and Community Services Association of NSW and the ACT to develop

GLBT and HIV sensitivity training packages for the aged-care sector. We are currently recruiting for this position and plan to hold a series of capacity building workshops across the aged-care sector in both Sydney and across regional NSW.

We know that the average age of people living with HIV is increasing. Ten years ago the average age was in the mid 30s, today it is in the mid 40s. We can expect that this age will increase even further over time. Today, we need research to paint a picture of the experience of growing older with HIV. If the minimal data we have is correct, then people living with HIV will need service-types and social support mechanisms that cater to the complexities of not only living with HIV, but getting older and getting older earlier.

This article has focused primarily on those who are living with HIV and are already experiencing ageing. We also need to understand the experience of those who are much younger and more recently diagnosed, who are likely to experience ageing in the decades ahead. Will this sub-population have unique experiences that need further consideration?

## Reference

1. This resource is available by contacting your local PLHIV organisation or AIDS Council or can be downloaded at: <http://www.acon.org.au/hiv/news/growing-older-with-HIV>

**Russell Westacott is Director of Client Services at ACON.**



# 'We don't have any of those people here ...'

By Jude Comfort, Rita Freijah, Barbara Horner, Alexandra McManus, Graham Lovelock and Michelle Hunter

Most people ageing with HIV in Australia are, and will continue to be, gay men. For those who avoided disclosing their sexuality throughout their lives or who have limited disclosure to a small circle, the prospect of dealing with aged-care services can be daunting.

For many older gay men diagnosed with HIV in the eighties or nineties, the concerns around disclosing sexuality are compounded by past experiences of stigma and discrimination due to their sexuality, with additional fears around disclosure of their HIV-positive status.

The GRAI research outlined in this article raises important issues that must be addressed in planning for the diversity of the Australian population – planning that needs to acknowledge the issues faced by the Australian cohort of gay men ageing with HIV. (Eds.)

## Introduction

GRAI (Gay, lesbian, bisexual, trans and intersex Retirement Association Inc.)<sup>1</sup> recently released the findings of a 12-month research project conducted in Western Australia (WA), looking at the accommodation and service needs of older non-heterosexual people. The research was supported through a Lotterywest Social Research Grant and involved collaboration between Curtin University, through the WA Centre for Health Promotion Research, the Centre for Research on Ageing, Curtin Health Innovation Research Institute and GRAI.

The project came about from formative research conducted by GRAI and researchers at Curtin University in 2006/07, confirming that older and ageing gay, lesbian, bisexual, transgender, intersex (GLBTI) individuals accessing retirement and residential aged-care services in WA

experienced unmet needs and fears of discrimination.<sup>2</sup> This was in line with other national and international research indicating that older GLBTI people were likely to be disadvantaged in the aged-care sector due to their minority sexuality. The research was used to develop best practice guidelines to assist providers to deliver more GLBTI inclusive services and help in addressing challenges faced by members of the GLBTI community.<sup>3</sup> This article discusses the background to the research and presents the best practice guidelines.

## Background

In addition to the usual issues facing older adults, such as loneliness, isolation, loss of autonomy and increasing dependence, older GLBTI individuals may experience further stressors.<sup>4</sup> These are usually associated with sexual orientation, disclosure of sexual orientation and/or gender identity to health care providers, discrimination, lack of legal recognition, little, if any, protection of lifetime partnerships, and limited opportunities to meet other older GLBTI people.<sup>5,6</sup>

Furthermore, the heteronormativity (presumption and preferences of heterosexuality) of retirement and residential aged-care facilities is a concern for many older GLBTI people. Heterosexual assumptions coupled with the notion of older people being asexual, can make GLBTI people feel that their same-sex relationships are not valued or understood and that partners will be excluded in care planning and decision-making.<sup>7</sup> Additionally Addis reports some older GLBTI people fear a lack of recognition and support of their 'families of choice' from service providers.<sup>8</sup>

Older GLBTI Australians grew up during a time where homosexuality was illegal, and those found to be engaging in homosexual activities were prosecuted. The negative attitudes of society in general towards homosexuality led to persecution, condemnation, hatred and discrimination, with homosexuality commonly viewed as a 'sickness, sin and disgrace'.<sup>9</sup> Consequently the GLBTI

population was concealed from the general population with few people disclosing their sexual orientation for fear of reprisal and/or prosecution.<sup>10</sup>

As a result, getting older for many GLBTI people can mean increased fear of being 'outed' after a lifetime of avoiding disclosure of their sexuality, or fear of lack of understanding and support as they seek assisted care. Concealment of identity renders older GLBTI people invisible and may result in service providers unintentionally failing to address their needs beyond the physical.

There is a growing body of research around GLBTI gerontology within Australia and internationally. Although there may be context specific considerations, recurrent key themes identified are:

- historical experiences of homophobia/discrimination
- current experiences of homophobia/discrimination
- concealment of identity – invisibility
- ageism within the GLBTI and wider communities
- impact of homophobia/discrimination on the quality of care delivered
- heteronormativity, and
- social isolation.

## Research methodology

The research outlined in this paper is unique in Australia as it sought to examine experiences and attitudes of service providers around GLBTI client issues. Organisational data were collected through a self administered Chief Executive Officers (CEOs) Survey and a separate Facility Survey to facility managers. Forty CEOs of retirement and residential aged-care organisations in WA with multiple facilities completed the CEOs Survey, with a response rate of 32.5% (n=13). The CEO Survey was also sent to single entity organisations and a 14.5% (n=23) response rate was achieved. Operational data were collected through a statewide *Facility Survey* sent to 320 retirement and residential aged-care providers in WA, with a response rate of 26% (n=83)

for this group. Qualitative data was collected through two focus groups.

## Results

The full findings in the final report are available at [www.grai.org.au](http://www.grai.org.au). A brief summary of some of the key findings are presented in this section. 86% of *Facility Survey* respondents were unaware of any GLBTI residents or supporting families currently or previously accommodated within their facility. Only 30% of respondents agreed that their facility recognises that GLBTI residents have specific needs. The majority of *Facility Survey* respondents (79%) agreed, or strongly agreed, that a resident's sexuality was not their concern, however over half (88%) indicated that a resident's beliefs and personal diversity were promoted within their facility's policies and procedures. The majority of *Facility Survey* respondents (66%) felt that they provided a GLBTI-friendly and trusting environment which 'treated everyone the same'.

Table 1 (on the following page) summarises the attitudes of facilities to GLBTI issues. The majority of facilities did not provide any training on GLBTI issues, and their policies did not address GLBTI issues.

## Best practice guidelines

An important outcome of the project was the development of best practice guidelines for retirement and residential aged-care providers in Western Australia which seek to encourage management and staff to adopt practices that create an inclusive environment, accepting and welcoming of all groups, including GLBTI people. The guidelines are also designed to provide an operational context whereby providers of retirement and residential aged-care are better able to recognise, understand and meet the specific needs of GLBTI people.

*continued overleaf*

**Table 1** Facility attitudes with regards to GLBTI issues (n=83)

	Strongly disagree n (%)	Disagree n (%)	Unsure n (%)	Agree n (%)	Strongly agree n (%)
Your Facility recognises that GLBTI residents have specific needs	4 (5)	18 (23)	33 (42)	19 (25)	4 (5)
Same-sex partners of a resident have the opportunity to be involved in that person's care	0 (0)	0 (0)	13 (10)	30 (38)	40 (50)
Your Facility provides a GLBTI-friendly environment	0 (0)	3 (4)	24 (30)	32 (40)	21 (26)
Non-judgemental language is used and promoted within your Facility's printed policy and procedure documents	1 (1)	1 (1)	14 (17)	32 (40)	33 (41)
All residents' beliefs and personal diversity (e.g. religious, cultural, sexual) are promoted within your Facility's policies and procedures	0 (0)	2 (3)	7 (9)	24 (30)	46 (58)
A resident's sexuality is not of concern to your Facility	2 (3)	7 (9)	8 (10)	29 (36)	34 (43)
Staff treat residents as individuals (not defined by their cultural/political/sexual identity) at your Facility	0 (0)	0 (0)	4 (5)	21 (26)	55 (69)
Your Facility provides a trusting environment where residents feel safe enough to disclose their sexual orientation	0 (0)	1 (1)	14 (17)	33 (41)	33 (41)
GLBTI issues are not important to your Facility	5 (6)	29 (37)	17 (22)	17 (22)	10 (13)
GLBTI residents' needs are openly discussed at your Facility	2 (3)	20 (26)	25 (45)	14 (18)	6 (8)
Other residents are encouraged to support a GLBTI-friendly environment	3 (4)	12 (16)	44 (57)	14 (18)	4 (5)

To achieve best practice for accommodating older GLBTI people five principles were identified:

1. inclusive and safe environment
2. open communication
3. GLBTI sensitive practices
4. staff education and training, and
5. GLBTI inclusive organisational policies and procedures.

### Implications for service providers

The findings of this research have a number of implications for providers of retirement and residential aged-care if they are to adequately meet the unique needs of older GLBTI people. It should be acknowledged that while a response rate of 26% of facilities (n=83) is not optimal, this rate is what can be expected when surveying such organisations.<sup>11</sup> Respondents included a variety of facilities across location (metropolitan – 53%, rural – 40%, remote – 7%), size (61% with staffing levels of 25 full-time equivalents or less) and ownership (55.6% not-for-profit).

It is clear that older GLBTI people currently accessing retirement and residential aged-care are a hidden population. Older GLBTI people in general do not feel safe to disclose their sexual or gender identity to

aged-care providers as a result of their past experiences of discrimination.<sup>12</sup> Additionally, concerns are raised regarding the fact that a large number of residential facilities are run by faith-based agencies.<sup>13</sup> Although some of these facilities may be accommodating to all seniors, others exclude potential residents (including GLBTI people) who do not adhere to their particular religious conventions.

Heteronormativity and homophobia exist within the broader community and they are also likely to exist in retirement and residential aged-care facilities.<sup>14,15</sup> It is essential that agencies provide inclusivity training for their staff at an organisational and facility level. Findings from this research indicate that few agencies currently make such training available for their staff, or have GLBTI-inclusive organisational policies and procedures that would assist in supporting long term change in attitudes and practices.

### The future

While these best practice guidelines were developed based on research completed in Western Australia, they have national merit. The nation-wide adoption of the guidelines developed as part of this research would provide a

starting point for fundamental national reform at an organisational level, and would lay the foundation for positive changes in retirement and residential aged-care facilities.

Although HIV does not exclusively affect gay men, issues around planning for aged-care have particular resonance for older gay men living with HIV. Some people living with HIV may require access to retirement and residential aged-care services at an earlier age than would generally be expected. Naturally occurring age-related conditions such as cardiovascular disease, diabetes, osteoporosis, some cancers and dementia are presenting at an earlier age for some people living with HIV, causing early onset of ageing.<sup>16</sup> This has implications for service providers, as the need to accommodate much younger people with complex and unique care requirements increases.

Further research is required to explore the implications of HIV-related early ageing for providers of residential aged-care; and the social dimensions of accommodating people living with HIV.



# Thriving and surviving: ageing well with HIV

By James May

James May speaks with three people who have lived with HIV for over twenty years about their experiences of living long-term with the virus and their perspectives on the changing social context of the epidemic in Australia.

**Ian** first tested for HIV in 1984, while living in Sydney, and was diagnosed HIV-positive. He says, aside from some initial fear amongst family and friends, he has never experienced any stigma from being open about his positive status. He says that even his relatives soon adjusted to the news, after a little education.

Since 1992, Ian has lived in northern NSW and believes this is somewhat responsible for his overwhelmingly favourable experiences. 'It's a colourful area which celebrates diversity, so it's easy to be open about my sexuality and HIV status.' Ian finds people are more aware about HIV these days, seeing it as a chronic, manageable condition.

Ian has never been confronted with the 'it's your fault' scenario and yet he's always been cautious about disclosure so as to avoid contending with people who might not be so open-minded. Interestingly, he says he gets a stronger reaction from people when disclosing his sexuality than his HIV status. 'Homosexuality still seems to provoke more fuss than the virus', he says.

He has always been nervous about disclosing his status to sexual partners, and says he probably always will be. 'I assume the worst, but 99% of the time I get a favourable response.' Ian says he always discloses his status during sexual

*continued overleaf*

encounters where anal sex is involved, or if he wishes to pursue a connection with someone.

As a highly social person, Ian has gone out of his way to participate in gay support networks and community groups. He has experience of HIV peer support in the Lismore region, where he found people to be isolated due to a lack of social skills and/or previous drug and alcohol issues. He says that staying connected to the community is extremely important in terms of thriving and surviving. 'Personally, I find it very useful to engage with other people's stories and avoid being consumed with my own.'

Although Ian is a great believer in Western medicine, in his 26 years spent with HIV he has explored many alternative therapies, including naturopathy, Chinese herbs, vitamins, yoga and massage. He says he did not commence standard HIV therapy for nine years because he never felt sick. 'I never thought the virus would kill me, although I'd always freak out when I came down with the flu.'

Although his health is great, he does have some concerns about the possible correlation between dementia, ageing and the long-term use of antiviral drugs. He is also concerned about cholesterol and cardiac health, although he regularly monitors this with his GP.

'Having a positive attitude and staying active is the most important thing.'

Ian has just completed a two week kayaking trip through the Great Barrier Reef.

**Marianne** has been HIV-positive for 21 years and she feels not much has changed in terms of stigma associated with HIV in the heterosexual community. She says, 'Most guys are shocked when I tell them. They don't want to use condoms. Also, the thought of having a relationship with someone, who in their mind could die young is too painful [for them] to consider. They say they want to be friends but I never see them again.'

According to Marianne, straight men don't know how to deal with the emotions that surface during disclosure and won't make an effort to learn about the realities of the virus. She has also lost several clients in her work as a beauty therapist after revealing her status. 'People can't help but see you as "different" – they're afraid I might infect them. It makes them feel vulnerable – as though it could've been them who was diagnosed with the virus.'

Marianne was recently discriminated against by a senior health specialist at a Melbourne hospital. The doctor agreed to carry out a routine, non-invasive procedure, but then pulled out when

she discovered Marianne's status. 'She insinuated that I was a drug user and shouldn't be sexually active.'

According to Marianne, the 'this can't happen to me' mentality is still out there. She knows of people in their forties who have recently seroconverted. 'Not having used condoms in their youth, many people of this generation are quite ignorant about the safe sex message.' Marianne believes that people should be educated from an early age, and says that girls need to know that it's okay to be assertive and carry condoms. 'People need to know there's a lot more to sex than penetration; there needs to be more humour in sex education as well.'

Marianne says it's difficult for positive women to find intimacy with heterosexual men. 'Some people tell me to become a lesbian, or they try to set me up with someone else who is positive. I don't want to think that I can only be with a guy who has the virus.' She says that many positive women don't bother dating because they can't deal with the possible consequences of disclosure, like rejection and feeling unworthy of love. 'I never give up hope of things changing. It helps me weed out the ignorant ones; it's made me more selective.'

Marianne surrounded herself with gay friends after the diagnosis, but felt isolated in the heterosexual community, despite meeting acquaintances through her fit, active lifestyle. She has always been very open about her diagnosis, leading her to get involved with various public education campaigns. Her first major media exposure was through being part of the Positive Women's triathlon team at the World Masters Games, in 2002.

Marianne's health has remained consistently strong. Complimentary medicines, diet and exercise have all played a pivotal role in this. She

Although his health is great, he does have some concerns about the possible correlation between dementia, ageing and the long-term use of antiviral drugs. He is also concerned about cholesterol and cardiac health, although he regularly monitors this with his GP.

survived with a minimal T-cell count and no medication for a long time. It was only in 2005, after a bout of pneumonia, that she needed to commence antiviral therapy. Although the medication is working well, she says she is looking forward to a treatment break.

‘HIV has been tough, but it’s made me realise what’s really important – friends, family, health, happiness – being involved in the world. It’s made me focus on the positive, not the negative. It’s made me aware of the mind-body-spirit connection; the importance of having discipline and never giving up.’

Marianne has just competed in the national power lifting championships and came fourth in a field of women which included world title holders.

**Dale** has been HIV-positive for 22 years. He says that many guys under 40 are blasé about the virus. ‘The “it won’t happen to me” syndrome is very prevalent and they’re happy to put themselves at risk.’ He says he has usually received great support from health services. The one exception was when a nurse at a major clinic in Melbourne was very condescending about his decision to take a HIV treatment break while undergoing chemotherapy for cancer. ‘I didn’t feel like my body could cope with both treatments at once, and she was very rude when I made the decision to stop antivirals. She didn’t give me credit for knowing what my own body needed.’

Dale says that positive people suffer far less discrimination these days. ‘Many people used to think they could catch it from casual contact [like kissing].’ He doesn’t venture into the gay scene anymore, because he says ‘the gay scene revolves around party drugs like ice and there’s no sense of community.’

His parents were fine about his HIV status, but his brothers were very uncomfortable, and he hasn’t seen them

much since the diagnosis. ‘They came to the hospital when I was sick with cancer, but we had no contact after that. I think the family carries a bit of guilt about the whole thing.’

Dale was in a serodiscordant relationship for three years, and the virus was never an issue. He is currently enjoying an open relationship with another positive guy. He has always had a healthy sex drive. Even after his initial diagnosis in his twenties, he remained highly sexually active. During that time he usually went to saunas for casual sex because disclosure there was less of an issue. He says that disclosure still doesn’t cause many problems, ‘as soon as I tell people I’ve been going for 22 years they relax’.

Dale has felt isolated living with the virus at times, although he’s always had close friends, as well as an aunt, to confide in. He also maintains contact with peers and support staff at the Positive Living Centre in Melbourne. ‘Tending to my plants and painting with acrylics is a great release as well.’ Dale has also been involved with the Positive Speakers’ Bureau for several years. ‘There’s a need to educate the heterosexual community, as well as young guys who are just coming out’, he says.

He’s had a few rough times with HIV, enduring side effects like diarrhoea and rashes whilst taking AZT during the early nineties. He was diagnosed with anal cancer five years ago and had to undergo three months of chemotherapy and radiotherapy. The cancer is now in remission and the combination of antivirals he is currently on has been working well for three years. ‘It’s given me a bit of a belly, but I feel fine other than that. My other combinations failed because I missed doses – I won’t do that again; it’s not worth the grief.’ He says that laughter is the best medicine. ‘I appreciate each day because you never know what might happen. Who knows?

I could wind up immune to these drugs.’

According to the three people interviewed here, the reality of living with HIV in the gay community has become far easier, whereas the situation is still quite difficult for their heterosexual counterparts. The woman I spoke with faces on-going ignorance within the heterosexual community, whereas the gay men generally had more favourable experiences in a social and sexual context. Many young gay men are actually quite blasé about the risk of HIV infection, according to the men I spoke to.

Interestingly, discrimination from health service practitioners was mentioned by two out of the three respondents. These situations left them feeling judged and disempowered.

All three participants stated that social and support networks are extremely important in terms of thriving and surviving and each person has actively sought to avoid being isolated by their diagnosis. Location, lifestyle and social skills play an important role in maintaining these connections and fostering health and well-being.

No-one I interviewed felt as though living with HIV had accelerated their ageing process, although many mentioned concerns about possible side-effects from long-term antiviral use, such as dementia and cardiac health issues. Each person experienced illness, to varying degrees, and has gone on to live active, healthy lives. Antiviral therapy, complimentary medicines, diet, exercise, and a positive outlook have clearly enabled this.

**James May is a writer of short fiction, theatre and freelance journalism. His work has been published in various magazines and anthologies.**



# New frontiers: exploring the psychosocial challenges of growing old with HIV

By Anthony Lyons, Rachel Koelmeyer, Jeffrey Grierson and Marian Pitts

As we enter the fourth decade of the HIV epidemic, what it means to become infected and to live with HIV has changed enormously. This is largely a consequence of advanced treatments that now make it possible for people living with HIV (PLHIV) to live into old age. Not surprisingly, the numbers of older people with HIV are growing rapidly. In the US, around 50% of all positive people are expected to be aged over 50 years by 2015.<sup>1</sup> A similar proportion is expected in Australia. In fact, a study of men who have sex with men in Australia has found the number of people living with the virus who are aged over 60 has increased by around 12% every year since the mid-1990s.<sup>2</sup>

This good news also means we are now facing new frontiers. What is it like to grow old with HIV? What are the challenges? How can older HIV-positive people best be supported in their senior years? While the overall quality of life for this group has improved through highly active

antiretroviral therapy (HAART), new challenges are emerging. Already we know that HIV-positive people who are aged over 50 have a higher incidence of hypertension, low bone mineral density, and lipodystrophy than their HIV-negative counterparts.<sup>3</sup> They are also more likely to develop age-related illnesses at an earlier age, including coronary artery disease, osteoporosis, and dementia.<sup>4</sup> The risk of heightened toxicity from combining antiretroviral drugs with those for ageing-related illnesses has also become a growing concern<sup>5</sup>, potentially threatening further improvements in the quality of life for older HIV-positive people.

Of course, the ingredients that make up a high quality of life extend beyond good health. Our living conditions, relationships, the ways we access and gain support, and many other aspects of our psychosocial circumstances all contribute to our overall sense of wellbeing. Over the past twelve years, six separate surveys known as *HIV*

*Futures* have been conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS).<sup>6-11</sup> Through these surveys, thousands of people from across Australia have described their challenges and experiences living with HIV. In the most recent survey, 92% were men (of whom 85% identified as homosexual), 7% were women, and less than 1% were transgender. Overall, 41% were aged over 50. Based on the findings, older people who are HIV-positive have good reason to feel optimistic about the future. However, there appear to be a number of challenges to attaining a high quality of life that need to be addressed. The following are some of the psychosocial areas from the *HIV Futures* surveys where such challenges have been identified.

## Economic and living conditions

At the time of the *HIV Futures 5* survey in 2005, Australian PLHIV who were aged over 50 were less likely

to be employed than the under-50s and tended to work less hours overall in paid employment. They were also more likely to be living in poverty. Alarming, around 37% of older positive people were living below the poverty line compared to 25% of the under-50s. On a positive note, data from the *HIV Futures 6* survey in 2008 shows that while the over-50s are still less likely to be employed than those under-50, there is no longer a divide between the two age groups with regard to living in poverty. In 2008, approximately 30% of both the under-50s and over-50s were living in poverty. The reduction in the proportion of older HIV-positive people living in poverty is likely to be due to an increase in the number of hours worked and an increase in overall household income.

### Relationships

Older HIV-positive people are less likely to be having sex than those under 50. However, a similar proportion of under-50s and over-50s report being in a regular relationship (44% and 41%, respectively). The difference between the age groups with regard to the proportion having sex is largely accounted for by fewer over-50s having casual sex.

### Stigmatisation and discrimination

Around a quarter of older HIV-positive people report recent instances of discrimination or being treated unfairly as a result of their HIV status. Such discrimination can come from health service providers, such as being avoided or having treatment refused, as well as in the workplace and when seeking accommodation. On a positive note, the over-50s tend to report fewer instances of discrimination than the under-50s.

### Support

While the over-50s are just as likely as the under-50s to use services targeting HIV-positive people, they are less likely to use non-PLHIV services, suggesting that older positive people have a greater reliance on the HIV support sector than their younger counterparts. Compared to the under-50s, the older group

also report receiving greater support from healthcare workers, general practitioners, and PLHIV organisations – highlighting that health professionals and PLHIV groups can have an important role to play in the lives of older HIV-positive people. The over-50s are more likely than their younger counterparts to know someone else who is HIV-positive and to feel supported by HIV-positive friends. Despite all this, with more than a third of older HIV-positive people taking medication for a mental health condition, such as depression or anxiety, there is an urgent need for more effective targeting of mental health support.

### Are we seeing a cohort effect among those ageing with HIV?

Programs and services that seek to enhance the quality of life for older HIV-positive people will need to take the above findings into account. However, longer term planning and the overall effectiveness of programs may well depend on the answer to one crucial question: to what degree do the psychosocial challenges and experiences of the current group of older positive people reflect a general pattern of ageing with HIV?

There are reasons to suggest that many of those in the current group of older people living with HIV have an experience of ageing that may not be reflected in future older positive communities. Large numbers of this group were infected in the 1980s and

1990s, at a time when living with HIV was a far more frightening and life threatening prospect than it is today. The vast majority were gay men, many of whom lost friends to AIDS-defining illnesses and who lived in fear of dying themselves. They also suffered greater impairment to their day-to-day functioning, while also having to confront a lack of employment and a host of issues around being accepted by a public that was more fearful of HIV-positive people (and arguably more homophobic) than today. In addition, we have seen changes in the treatment regimens available (from AZT monotherapy to HAART) and in treatment guidelines over the history of the epidemic. All these experiences, plus others, are likely to have shaped what it means to these people to be HIV-positive, as well as influencing the levels of assistance they require from individuals and organisations.

The consequences of these experiences may not all be negative. Having survived the pre-HAART era, many older people living with HIV may be particularly resilient. Living into old age, despite earlier prospects of dying young, may also appear a blessing to some and therefore a reason to feel positive about their lives. In fact, drawing again on *HIV Futures* data, when we compare positive people's

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Having survived the pre-HAART era, many older people living with HIV may be particularly resilient. Living into old age, despite earlier prospects of dying young, may also appear a blessing to some and therefore a reason to feel positive about their lives.

ratings of their overall wellbeing, not only do they average at the positive end of the scale, they are generally no lower for the over-50s than they are for the under-50s.

The impact of having been diagnosed in the pre-HAART era also becomes apparent when compared with those who were infected later. People, aged over 50, who were infected pre-HAART, tend to rate their wellbeing slightly higher than those infected post-HAART. They are also more likely to receive support from HIV-positive friends, but less likely to access and receive support from PLHIV organisations.

What all this means is that identifying the challenges of ageing with HIV may not be straightforward. The experiences of those who were infected pre-HAART may paint a different picture to the way ageing with HIV might look in the future, especially as more of those who were infected after the introduction of HAART enter old age.

### Where to from here?

To understand the psychosocial challenges of growing old with HIV, an important step is to monitor changes in the quality of life of older people living with HIV from year to year. Only through such longitudinal research can we distinguish between the needs and experiences of the current older group and the general, more systemic patterns related to growing old with HIV.

Despite rapid growth in research on ageing with HIV, very little of the available data is longitudinal. Simple comparisons between older and younger people may not provide the necessary framework for identifying all the experiences and challenges of growing old with HIV. For this reason, researchers at ARCSHS, in collaboration with NAPWA and other PLHIV organisations, will soon be launching 'LifeTimes', a survey that comprehensively explores the health and wellbeing of older HIV-positive gay men and their HIV-negative counterparts. With the survey to be repeated every year, respondents will be given an opportunity to keep the PLHIV support community continually informed about their changing experiences of growing older with HIV.

How quickly and effectively health and social service providers adapt to and cope with this new frontier will depend on having an accurate, detailed and up-to-date picture of the changing health and psychosocial needs of a rapidly ageing HIV-positive community. This is especially so for those who were infected post-HAART as they enter old age and transform the demographics of the current older community. Most critical of all will be the need for the HIV and aged-care sectors to work together, with a combined focus on both the clinical and the psychosocial, to ensure that programs and policies effectively address the diverse and changing needs of this community.

How quickly and effectively health and social service providers adapt to and cope with this new frontier will depend on having an accurate, detailed, and up to date picture of the changing health and psychosocial needs of a rapidly ageing HIV-positive community.

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**The Australian Research Centre in Sex, Health and Society (ARCSHS) is a leading national and international centre for research on sexuality, health and gender. ARCSHS conducts interdisciplinary research on sexuality and health, and promotes social justice outcomes using its research.**



# Ready or not: addressing stigma and promoting wellbeing of people living with HIV in aged-care

By Dr Catherine Barrett, Associate Professor Anne Mitchell, Lizzi Craig and Dr Liz Crook

## Introduction

Given the increasing number of people ageing with HIV, it is important that aged-care services are ready to meet their care needs.

The aged-care sector currently supports a large number of older Australians to remain in their own homes, with residential services provided to about 5% of people over 65 years. These supports need to take into account particular issues faced by older people living with HIV. However, recent studies indicate that aged-care services do not understand the needs of older HIV-positive people and discriminate against this cohort because of fear of HIV. These findings are of particular concern in the context of a recent study of the health and psychological

wellbeing of HIV-positive, older gay men. The study found that:

*'... the strongest predictor of subjective wellbeing was men's reported history of discrimination from medical service providers around their HIV status, therefore highlighting perceived stigma as a crucial element in overall wellbeing.'*<sup>1</sup>

This article looks at the readiness of aged-care services to meet the needs of people living with HIV from the perspective of older HIV-positive people (and those assumed to be HIV-positive), and from the perspective of people working in aged-care. We then examine these perspectives in the current context of aged-care service provision, to illustrate the need for a person centred strategy to educate aged-care service providers.

## Client experiences of aged-care

In 2008, a study was undertaken in Victoria to explore the experiences of older gay, lesbian, bisexual, transgender and intersex (GLBTI) people in aged-care.<sup>2</sup> The *My People* study included interviews with eight gay or bisexual men, one of whom disclosed being HIV-positive. Most of the men raised concerns about the readiness of aged-care services to care for people who are HIV-positive, or assumed to be so. Several described how carers assumed that they were HIV-positive because they were gay. For example, Andrew described having a home care provider from his local council visit his home daily to shower his partner Bill. Andrew described inadvertently

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revealing that he and Bill were in a relationship and noted that in response *“The carer wouldn’t really shower Bill after that. Bill was blind, deaf, full of arthritis and needed all the help going. I think the carer was concerned that we were gay. The guy thought: he’s gay and has he got something else wrong with him? He was worried about HIV/AIDS. That’s what I think. I phoned the council and told them. They were very good. I told them I didn’t want him back.”*<sup>3</sup>

Other interviewees described aged-care service staff refusing to physically touch them or ‘double gloving’ for all physical contact with them when it was revealed that they were gay. As a consequence all the interviewees reported that they were reluctant to access aged-care services and that they hid their sexual identity when accessing services to avoid being assumed to be HIV-positive.

The study was small and limited to the experiences of gay men in Victoria. However, the findings indicate that some aged-care service providers do not understand HIV, with the result that their responses are discriminatory. This is concerning given the finding that discriminatory responses are a crucial element affecting overall wellbeing.

### Staff perspectives

The views of aged-care service providers on caring for HIV-positive people were described in a 2008 study

exploring their perspectives on the care of GLBTI clients.<sup>4</sup> The study included three focus groups and 16 interviews with aged-care service providers. Participants were given a scenario of a newly admitted HIV-positive client, and they were asked to describe how staff in their service would respond to this client. Most of the study participants reiterated the misinformation and fear of contagion identified in the *My People* study. One interviewee reported that her colleagues:

*“... would over-glove; there are always staff who go too far; I don’t think staff have nursed enough HIV, so they would freak out.”*<sup>5</sup>

Another reported that:

*“... some staff might steer away, not go near him, and avoid nursing him. They need the facts of how HIV is transmitted and whether there going to be any dangers for them.”*<sup>6</sup>

These responses were fairly typical of the views expressed by other interviewees. The fear of the contagion of HIV, and the assumption that all gay men are HIV-positive, was also identified in the focus groups. One focus group was held in a high-care facility where staff had recently identified that a resident was gay. In reference to this resident, one of the focus group participants reported that:

*“We don’t have the information on whether he has AIDS. I feel sorry for the poor personal care attendants that*

*go in there and don’t wear gloves to protect themselves. If they get AIDS who are they going to sue?”*<sup>7</sup>

These views demonstrate the fear of contagion that is associated with ignorance about HIV and its transmission. Many of the study participants reported that they had not received any education around HIV since the ‘Grim Reaper’ Australian national television campaign of the 1980s. Perhaps then it is not surprising that they fear HIV-positive clients.

The importance of educating aged-care service providers was reiterated in a study conducted in aged-care across Sydney, in which service providers were invited to complete a survey about their knowledge of HIV and their concerns. Of the 106 respondents, 55% said they worried about catching HIV from a resident, and 62% said that they worried about passing on HIV to their families after caring for the resident.<sup>8</sup> This study reinforces the importance of educating aged-care service providers to ensure the wellbeing of older HIV-positive people.

### A framework for education to promote wellbeing

The opportunity exists to educate aged-care service providers about HIV in a way that addresses fears of contagion and promotes the wellbeing of HIV-positive clients. This can be achieved by focusing on person-centred care. A person-centred approach is generally accepted in aged-care and has been identified by the Department of Health in Victoria (2004) as a strategy to improve care for older people.<sup>9</sup>

The person-centred approach adopted in our training, which is co-ordinated by Gay and Lesbian Health Victoria, sets out to improve outcomes for the care of people living with HIV by addressing the needs of both staff and clients. The education begins by inviting staff to describe their fears, assumptions and beliefs. This provides

The opportunity exists to educate aged-care service providers about HIV in a way that addresses fears of contagion and promotes the wellbeing of HIV-positive clients. This can be achieved by focusing on person-centred care.

the opportunity to challenge myths and provide factual information, including reinforcing universal precautions. Staff can then understand the experience of aged-care from the perspective of the HIV-positive client. To achieve this we use narratives from older HIV-positive people, these providing humanising accounts of the experience of living with HIV. This encourages service providers to look beyond the virus to the experience of the person living with the virus. The narratives also demonstrate for staff how a discriminatory response can impact on client wellbeing.

This educational framework needs to take into account the current context of aged-care services. For the past decade, the aged-care section of the Victorian Department of Health has experienced a number of challenges. In 2004, concerns about care and staff recruitment led to a Senate inquiry into the aged-care workforce.<sup>10</sup> The inquiry found that although the numbers of older people requiring aged-care services has increased, the aged-care workforce has decreased. Furthermore, the inquiry recognised that poor pay and increasing bureaucratisation of aged-care made it difficult to recruit and retain staff. While the inquiry noted a shortage of appropriately qualified staff in all health sectors, it reported that this was most notable in the aged-care sector. The inquiry also uncovered that the effects of an inappropriate skills mix included increased stress and a potential decrease in the quality of care.

Education of aged-care service providers also needs to take into account high turnover of staff, low literacy, low morale and significant workloads. There is also a need to recognise that many who work in aged-care services are motivated by good intent – that they would provide a higher standard of care if the education were provided to show them what was required. For example, in the study

described earlier by Cummins et al.,<sup>11</sup> aged-care service providers indicated that they were concerned about HIV contagion but were more worried (60% of respondents) about not knowing how to care for a resident with HIV. Aged-care service providers deserve to be given the information they require to do their job well.

### Conclusions

Until aged-care service providers are educated about the needs of people in their care living with HIV, their responses will continue to be driven by misinformation and misplaced fears, and they will continue to miss the opportunity to promote the wellbeing of this client group. The educational model described in this article involves exploring staff and client narratives as a way of addressing staff fears and meeting client needs. The narratives told by older HIV-positive people provide aged-care services providers with the opportunity to understand their clients' journeys, including challenges encountered and overcome, and their experience of co-morbidities. This model needs to be considered by those providing services to older people in residential care, home care, community care, rehabilitation and acute care.

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# Regional Snapshot: HIV in China

By Abigail Groves

With estimates that HIV prevalence is around 0.05%, China is considered a low-prevalence country. However, its enormous population of 1.3 billion people means that there are large numbers of people living there who are HIV-positive. Current estimates suggest there are about 740,000 HIV-positive people living in China today. This is only an estimate, because rigorous HIV surveillance and reporting is still a fairly recent development there. The total number of China's reported cases of HIV is 326,000, which means that more than half of the positive people living there have not been diagnosed or reported. Some 54,000 deaths from AIDS have been reported, though it is likely that there have been more.<sup>1</sup>

Prybylski and Wilson argue that HIV epidemics in Asia typically begin with infections among injecting drug users, which then spread to sex workers and their clients.<sup>2</sup> These 'second wave' epidemics are augmented by infections among men who have sex with men – creating an epidemic that is concentrated among these three risk groups. This pattern can be seen

in China, where significant numbers of HIV diagnoses first emerged among injecting drug users; until 2003, injecting drug use was the most common mode of HIV transmission in China. China is a huge country geographically, as well as in terms of population and, although HIV has been reported in every province, diagnoses were concentrated in the provinces of Yunnan, Guangxi, Sichuan, Xingjiang and Guangdong.<sup>3</sup> These are the provinces closest to the Golden Triangle and the Golden Crescent, and are centres of China's trade in illicit drugs. It is thought that HIV diagnoses in these provinces represent about 70–80% of the national total.

These provinces are also home to many of China's ethnic minorities, who are disproportionately represented among those diagnosed with HIV. Ethnicity is a highly sensitive subject in China, which is overwhelmingly dominated by Han Chinese, who make up 92% of the population; ethnic minorities are often socially and economically marginalised. One author suggests that the ethnic groups who make up the other 8% of

China's population account for 36% of HIV diagnoses.<sup>4</sup> Jing and Worth observe that 'Chinese health officials are still extremely reluctant to talk about the close association of drugs, HIV and ethnicity'.<sup>5</sup>

## Sex workers

By 2007, heterosexual sex had overtaken injecting drug use as the main driver of the HIV epidemic in China. Heterosexual transmission, though, is largely concentrated among female sex workers and their clients. Sex work has always existed in China, but the sex industry has grown with the de-regulation of the economy.<sup>6</sup> For example, Guangdong, in the south, was one of the first provinces to 'open up' to the west and to a market-driven economy; it is now China's most populous and most prosperous province. Its thriving manufacturing industries have attracted millions of workers from other provinces; by 2008 it was estimated that 20 million people had migrated to Guangdong from other parts of China. It was also estimated that there may be up to 500,000 sex workers in Guangdong.

HIV prevalence remains low among sex workers in China, with one study showing a national prevalence rate of less than 1%<sup>7</sup>, but it is higher in high prevalence areas. The Chinese government has focused significant HIV prevention efforts on sex workers, in an attempt to increase condom use and awareness of HIV and STIs. This has been successful to some extent, with the level of condom use reported by sex workers increasing dramatically in the last ten years.<sup>8</sup> The sex industry is very diverse, with working conditions varying enormously according to where women work. As in most countries, the level of HIV risk that sex workers face tends to fall as the level of control that sex workers are able to exercise over their work increases.

### Men who have sex with men

Of particular interest to many Australian readers is the situation among gay men. In its 2010 UNGASS report, China noted that ‘the occurrence of new infections has been brought under control to a considerable degree,’ but added the qualifier ‘with the exception of MSM populations’.<sup>9</sup> The rapidly rising prevalence of HIV among gay men is one of the most worrying aspects of the epidemic in China. Men who have sex with men were not identified as a priority group for HIV prevention until recently; prevention focused largely on injecting drug users and female sex workers. In contrast to many western countries, men who have sex with men formed a fairly small proportion of total HIV infections: even in 2007, sex between men accounted for just 12.2% of diagnoses. By 2009, however, 42.2% of new infections were acquired through male-to-male sex.<sup>10</sup>

Moreover, HIV prevention among men who have sex with men in China faces significant obstacles. Historically, homosexuality has been heavily stigmatised in China. While recent years have seen the emergence of gay bars and clubs in many cities, Zhang says that ‘concealment of their sexual identity is part of everyday life for gay

men in China’<sup>11</sup>. The ancient Confucian value of filial piety is still very strong in China, and gay men – many of them an only-child – are under enormous pressure to marry and continue their family line. Most of them do so, with estimates that as many as 80–90% of gay men in urban areas marry under family pressure.<sup>12</sup> For men with HIV, the burden of secrecy is intense. Most of Zhang’s respondents kept their sexuality and their HIV status secret from their families. Moreover, the level of stigma attached to HIV made concealing their status an ‘absolute necessity’, even within the gay community; a situation that does not encourage the formation of peer-led responses to HIV.<sup>13</sup>

### China’s blood trade

Up until 2007, some 23.6% of all China’s documented cases of HIV (more than 50,000 people) had been caused by participation in China’s trade in blood – that is, the sale of blood and blood products such as plasma. The scale of the HIV epidemic caused by commercial trade in blood products is probably unique to China, and the problem has its origins in government policy. In the mid-1980s, the Chinese government prohibited the importation of blood products such as plasma, precisely because HIV had been detected in some imported products. This change in policy led to a rapid growth in China’s domestic production of blood products, but this took place in the context of a rapidly de-regulating economy. The emerging industry was profit-driven and paid blood donors were actively recruited from poor communities. Infection control was often non-existent and large numbers of donors were injected with infected products. This was particularly the case in the province of Henan, which has one of the highest levels of HIV prevalence in China – driven largely by the blood industry. By 1998, when the government acted to regulate the blood industry, thousands had been infected. The government’s official estimate is that there are 57,000

people currently living with HIV who were infected through the blood trade. This estimate, though, is thought to be ‘low’, as many of those affected came from poor rural communities without access to HIV testing; those who died without ever being tested were not accounted for in official statistics.<sup>14</sup>

### Government response

China’s national response to HIV changed markedly in 2003, as the country’s government underwent a generational change. On World AIDS Day in 2003, new Premier Wen Jiabao publicly shook hands with HIV patients in a hospital in Beijing – a first for the Chinese leadership. The SARS epidemic, which presented an alarming wake-up call on the importance of protecting public health, is also thought to have influenced the shift in government policy. From 2003, the government moved decisively to improve its response to HIV, introducing the ‘Four frees – one care’ policy. This policy aims to provide free counselling and testing, free ART treatment for people living in rural areas, free treatment for pregnant women with HIV, free education for children orphaned by AIDS, and economic assistance to households of people living with HIV.<sup>15</sup> Implementation is far from complete and human rights advocates are critical of the Chinese government’s treatment of people with HIV.<sup>16</sup> But the Chinese response has also delivered some impressive results, with the national budget for HIV prevention and care almost trebling between 2003 and 2008. The Chinese government has also embraced some harm minimisation initiatives, introducing needle exchange programs and methadone treatment in many areas; China now has more drug replacement clinics and needle social marketing programs than any other country in Asia. In 2009

*continued on page 46*



# 'Can you Imagine a World AIDS Conference without the Red Umbrellas'?<sup>1</sup>

By Michael Williams

Most of the coverage of the 2010 International AIDS Conference (IAC) in Vienna has focused on novel developments in clinical research, notably the CAPRISA microbicide trial and Professor Sharon Lewin's excellent plenary on a future cure for HIV. Less remarked upon, but not entirely absent from the reporting<sup>2</sup>, is the doubtful participation in future conferences of affected groups such as sex workers.

This is an issue because the IAC 2012 is in Washington DC. While the United States was applauded for recently repealing its prohibition on the entry of people living with HIV<sup>3</sup>, its immigration laws (like most of the western world's) are discriminatory in their exclusion of individuals with past criminal convictions. Everyone applying to enter the US must declare these convictions on their visa or visa waiver application. As

Turkewitz writes, these 'strict US travel regulations ban two groups heavily impacted by HIV – sex workers and those using illicit drugs'<sup>4</sup>. If a prospective traveller declares that he or she has no convictions, they may be excluded if the US believes they have. Increased information sharing between countries, and the US online visa waiver system (ESTA), means that individuals so tagged can be prevented from boarding a plane.

This is precisely what happened to my friend and colleague, the scholar and sex worker activist Cheryl Overs. On 15 June 2010, Overs was at Heathrow about to board a plane to New York when she discovered her ESTA application had been refused. According to the US immigration official at the airport this was because of alleged and unspecified convictions dating back to the 1970s.<sup>5</sup> Overs has been questioned before on entering the

US because, as one official informed her, her 'profile matches that of a person likely to be trafficking in persons'. While the official in June 2010 did not specify what the alleged convictions related to, it was clear from previous encounters that they concerned Overs' work within the sex industry some 30 years ago, and her subsequent sex worker activism.

Pursuant to the US *Immigration and Nationality Act*<sup>6</sup>, the '[g]eneral classes of aliens ineligible to receive visas and ineligible for admission' include those convicted of 'a crime involving moral turpitude' and those falling under the category 'prostitution and commercialised vice'<sup>7</sup>. This includes any alien who:

*'... directly or indirectly procures or attempts to procure, or (within 10 years of the date of application for a visa, admission, or adjustment of status) procured or attempted to procure or to*

*import, prostitutes or persons for the purpose of prostitution, or receives or (within such 10-year period) received, in whole or in part, the proceeds of prostitution ...'*<sup>8</sup>

Extraordinarily, the bans apply even if the prostitution, or profiting from prostitution, occurred in a country where prostitution is not illegal.

It is more than ironic that Overs was travelling to New York to attend a meeting of the Technical Advisory Group (TAG) to the UNDP's Global Commission on HIV and the Law. This is a group of scholars and experts examining, and arguing for repeal of, unjust laws and practices which impact on communities' vulnerability to HIV. The TAG has since issued a statement that voices its concern over the incident.<sup>9</sup> The statement also:

*'Requests UNDP to bring this matter to the attention of the International AIDS Society so that it may take appropriate action to avoid similar events impacting negatively on participation at the International AIDS Conference to be held in Washington in 2012.'*<sup>10</sup>

On one level, Overs' refused entry to the US is not surprising because the US government has long treated sex work and trafficking as indivisible. It is a conservative, Christian country, with a loud and powerful group of sex-negative women claiming to be feminists, and a group of radical feminists influencing government policy on the treatment of sex work. The President's Action Plan for AIDS Relief (PEPFAR), which distributes aid in resource poor countries, only provides funds to bodies which sign a pledge to oppose prostitution. Unless this is agreed to, the organisation does not qualify for funds. Consistent with this approach, a great deal of money has been directed to large, usually anti-trafficking groups which set out to 'rescue' those in the sex industry, irrespective of their trafficked status, or indeed their express wishes.

Overs' experience portends the difficulties that sex workers – and

those who have used drugs – may encounter as they attempt to enter the US for the IAC 2012.<sup>11</sup> A considerable number of sex workers (and groups representing illicit drug users) attend and participate in these pivotal conferences. Presumably, many of their members will have convictions because their lives are criminalised and stigmatised; subject to both formal legal sanction and discriminatory enforcement practices in their home countries, reinforced by pressure from the US. It is anyone's guess what action the US will take to remedy the potential exclusion of IAC attendees. It could reform its migration statutes, though this is considered improbable.<sup>12</sup> A suggestion currently on the table is that the issue be solved by a temporary arrangement that would permit sex workers and drug users to apply for an exemption to attend the conference.<sup>13</sup> Sex workers have dismissed the idea because to make such an application necessitates effectively registering as an undesirable person with the US immigration authorities.<sup>14</sup>

This puts IAS in a difficult position. Overs questioned 'what was IAS thinking rushing into a US conference as soon as the PLHA ban was removed? Have they learned nothing about the human rights of affected communities since we boycotted the San Francisco conference?'<sup>15</sup>

Surely the US and the International AIDS Society cannot host an International AIDS Conference attended only by scientists, physicians, and academics, whose lives are far removed from the global community of people living with, and vulnerable to, HIV. Surely one of the enduring lessons, from both successful and failed responses to HIV throughout the world, is that no credible strategy to combat the disease can be crafted without the participation of those communities most affected. It is hoped that people living with HIV show solidarity with other marginalised groups in advocating for the repeal – not just in the US but everywhere – of laws that ban entry for individuals based on stigma and ignorance.

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3. AFP. (2010, 4 January). *Rights Groups Laud End of US HIV/AIDS Travel Ban*.
4. Turkewitz, above n 1.
5. Overs denies having ever been convicted of any offence and imagines that any conviction must be the result of identity fraud. However, she cannot prove that to the US authorities because she can only access records for the previous 10 years. This raises the question of whether the Australian Government provides more information about its citizens to US Homeland Security than it does to its citizens.
6. 8 U.S.C. 1001, cited on US Department of State, 'Classes of Aliens Ineligible to Receive Visas' (accessed 10 September 2010) and on United States Immigration, 'Classes of Excludable Aliens Ineligible to Receive Visas' (accessed 10 September 2010).
7. *Ibid.*, sec. 212 [8 U.S.C. 1182].
8. *Ibid.*, Seshu also spoke out about Overs' problems entering the US in her plenary at the IAC, sounding incredulous that the US refuses entry on the basis that a person has been convicted of a crime of 'moral turpitude': above n 1.
9. Global Commission on HIV/AIDS and the Law Technical Advisory Group. 'Refusal of entry to Ms. Cheryl Overs, Member of the Technical Advisory Group', 17 June 2010.
10. *Ibid.*
11. Turkewitz, above n 1.
12. *Ibid.*
13. *Ibid.*
14. *Ibid.*
15. Private correspondence between author and Ms Cheryl Overs (10 September 2010).

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# Holy writ vs. legal right: reflections on the Global Commission on HIV and the Law and religious ideologies

By John Godwin

Religious fundamentalism is threatening international HIV responses on a number of fronts. In diverse contexts, conservative Islamic and evangelical Christian influences brand men who have sex with men (MSM), transgender people, sex workers and people who use drugs as sinful and criminal.

The HIV response demands an evidence-based approach, not one based on ideology and sexual moralism. It is timely that action is being taken by the United Nations (UN) at the global level to examine the evidence of the harm to HIV responses caused by laws and police practices that target marginalised populations. This will also require an assessment of the role of religion in shaping laws and law enforcement practices.

## The Global Commission on HIV and the Law

In June 2010, the United Nations Development Programme (UNDP) announced the establishment of the Global Commission on HIV and the Law.

The Commission comprises 14 international experts, including Hon. Michael Kirby, former Justice of the High Court of Australia (who will also co-chair the Commission's Technical Advisory Group), Dame Carol Kidu MP from Papua New Guinea, and Charles Chauvel MP, New Zealand Labour Party politician and lawyer. Cheryl Overs, sex worker rights activist and academic (based at Monash University and at the Paulo Longo Research Institute), is a member

of the Commission's Technical Advisory Group.

Over the next year, the Commission will be holding regional hearings in Africa, Asia, the Caribbean and Eastern Europe. The primary focus of the Commission will be criminal laws affecting MSM, sex workers, people who use drugs and people living with HIV. The Commission is tasked with bringing an evidence-based approach to these issues.

The Commission comes at a time when the influence of religious fundamentalism is manifesting in extremely disturbing events across the globe. Evidence-informed dialogue may prove difficult with those who oppose decriminalisation based on ideology, rather than by reference to empirical data on the impacts of criminalisation on health and human rights.

## The global 'wave of hate'

The last two years has seen a surge in damaging legal developments across the globe that either were initiated by, or found vocal support from, religious interests.

### Africa

Archbishop Desmond Tutu has referred to the 'wave of hate' currently faced by gay men and transgender people in Africa.<sup>1</sup> This hatred is legitimised by punitive laws and breeds violence and discrimination. It is a hate that is blind to the critical importance of engaging those most-at-risk of HIV as partners in HIV responses.

Influenced by American evangelical Christians, a member of the Ugandan

parliament introduced a shockingly draconian *Anti-Homosexuality Bill* in 2009. The Bill proposed the death penalty for people living with HIV who engage in homosexual activity.<sup>2</sup> The government was pressured into declining to support the Bill only after it provoked outrage from the international community, including threats from donors to discontinue aid.

In Senegal, more than 50 arrests have occurred in the last two years for homosexual conduct, with Muslim leaders calling for harsh punishments.<sup>3</sup>

In Malawi, a man and his transgender partner were sentenced to 14 years prison for sodomy in 2010. The couple were later released, only after meetings with UNAIDS and the Global Fund to Fight AIDS, TB and Malaria secured a presidential pardon – and despite the position of the Malawi Council of Churches in favour of criminalising homosexual conduct. While issuing the pardon on humanitarian grounds, the President reinforced the punitive legal and religious status quo, stating:

*'These boys committed a crime against our culture, against our religion, and against our laws.'*<sup>4</sup>

In Kenya, where sodomy is an offence punishable by 14 years imprisonment, the Kenya Medical Research Institute was attacked by violent mobs in February 2010 for providing HIV services to MSM.<sup>5</sup> In support of the protests, religious leaders from the Council of Imams and the National Council of Churches criticised the government for 'providing counseling services to these criminals' and demanded that the office that had been providing services to MSM be shut down.<sup>6</sup>

The moralistic approach to sexuality is also reflected in a trend towards criminalising transmission of HIV, with a notable increase in the number of African countries enacting HIV-specific offences over the last few years.<sup>7</sup>

### Middle East, Malaysia and Indonesia

Punitive laws are enforced against MSM in many countries where the legal system is based on or influenced by Islamic Sharia law. Recent reports

include 25 men arrested in Syria in June 2010, and 25 detained in raids in May in Malaysia.<sup>8</sup>

In Indonesia, the Aceh legislature enacted a law in 2009 that provides for penalties for homosexual acts of 100 lashes or eight months imprisonment. The status of the law remains unclear, as it awaits approval from the Governor. Also from Aceh, there are reports that Sharia police harass and threaten transgender people (*waria*) who work at beauty parlours, on the grounds that Sharia law prohibits men working in female environments.<sup>9</sup>

In March 2010, the Asia Conference of the International Lesbian, Gay, Bisexual, Transgender and Intersex Association (ILGA), due to be held in Surabaya, Indonesia, was cancelled due to threats from the radical Islamic Defenders Front.<sup>10</sup> The conference organising committee had obtained a police permit to hold the conference. The permit was withdrawn on the grounds that attacks by Islamic groups were anticipated. The police claimed that they were unable to guarantee the safety of those attending the conference. When Islamic groups proceeded to stage a protest, the conference participants were forced to take refuge for fear of imminent violence.

In April 2010, the Islamic Defenders Front interrupted a three-day human rights training workshop for *waria* in West Java. Islamic Defenders Front members reportedly stormed the hotel where the workshop was being held, destroyed property and assaulted participants. Rather than protecting rights of freedom of assembly, orders were given by local public security officials to the National Human Rights Commission to stop the event.<sup>11</sup>

### *Pacific*

The Pacific Sexual Diversity Network has warned that the rise of fundamentalist Christian churches in the Pacific is generating increased stigma and hostility towards sexual minorities.<sup>12</sup>

In Papua New Guinea, efforts by the Minister for Community Development Dame Carol Kidu and others to introduce a Bill to decriminalise homosexual conduct and sex work have been

opposed by some church leaders, who have referred to it as the 'immoral Bill'.<sup>13</sup>

In Fiji, the situation is complex. On the one hand, progress has been made in decriminalising homosexuality, despite protests from Christian and Muslim leaders. On the other hand, sex workers have been targeted by punitive policing backed by religious groups.<sup>14</sup> In 2009, Fiji's New Methodist Church and police organised a coordinated crackdown on sex workers. The intimidating tactics employed were reported as follows:

*Prostitutes who did not heed police warnings to get off the streets were summarily trucked to a bridge over an ocean inlet where they were ordered to make the six-metre leap into the water. But, according to several of the women, Christian idealism sometimes broke down at this point – they were made to service the arresting officers and had their purses and mobile phones stolen ... Others had their heads shaved. Some were made to run alongside police vehicles in Suva's streets. Under police escort, they also had to attend Sunday afternoon crusades.*<sup>15</sup>

While the New Methodist Church has since lost favour with the military regime, the punitive approach to sex work continues in Fiji. The *Crimes Decree 2009* introduced very strict prohibitions on sex work, which for the first time criminalises clients and male sex workers, as well as female sex workers.

### **Meanwhile in the corridors of the UN ...**

The tension between religious ideologies and evidence-based approaches to public health and human rights has also been on display at the UN.

In June 2010, the UN Rapporteur on the Right to Health reported to the UN Human Rights Council on decriminalisation of consensual sexual conduct.<sup>16</sup> The Rapporteur, Anand Grover, has worked since the 1980s as a lawyer championing HIV-related human rights in India. His report to the Human Rights Council succinctly summarises how laws criminalising homosexuality, sex work and the

non-intentional transmission of HIV undermine the enjoyment of the right to health. He makes a number of recommendations to UN member States to decriminalise same-sex sexual conduct, sex work and non-intentional HIV transmission (see breakout box on the following page).

States that spoke at the Human Rights Council to oppose the recommendation that sex between men be decriminalised were Algeria, Bangladesh, Botswana, Egypt, Iran, Nigeria (on behalf of the Africa group), and Pakistan (on behalf of the Organization of the Islamic Conference). Bangladesh went so far as arguing that homosexual men and transgender people are not marginalised (notwithstanding section 377 of the *Penal Code of Bangladesh*, which provides for life imprisonment for homosexual acts). Pakistan accused the Special Rapporteur of bias and criticised the report for focusing on a 'negligible group'. Brazil, Netherlands, Norway and Switzerland expressed strong support for the Special Rapporteur.

In the Human Rights Council debate, the USA stated that it could not support the report's recommendation to decriminalise sex work. USA still maintains its anti-prostitution policy, introduced during the Bush administration as a result of pressure from religious groups. The anti-prostitution policy requires agencies that receive USAID funding to oppose decriminalisation of sex work.

The way in which UN member states responded to the Rapporteur's report gives an indication of the controversial territory that the Global Commission on HIV and the Law is required to navigate in its hearings and recommendations. Religion clearly has a role in influencing state positions. This has also been evident in the recent failed effort to refuse UN consultative status to the International Gay and Lesbian Human Rights Commission, a campaign that was led by Egypt with backing from Malaysia, Pakistan, Saudi Arabia and a number of other countries.<sup>17</sup>

*continued overleaf*

## The leadership challenge

The clash of religious ideologies with evidence-informed approaches forms part of the overall political context in which the Global Commission on HIV and the Law is operating. The Commission will be adopting a transparent process, including public hearings and ‘interactive dialogue mechanisms’ through ‘social networking and new media technology’.<sup>18</sup> This will provide opportunities for a broad range of views to be heard, including from opponents of rights-based approaches.

In its findings and recommendations, the Commission needs to avoid the risk of preaching only to the human rights converted. Identifying champions for rights-based approaches from within Islamic and Christian communities is strategically important if recommendations are to be heard where it counts. Constructive engagement with faith-based organisations needs to occur. Leadership from within faith communities is required to reach those who are skeptical of human rights and to win them over with evidence-based arguments.

There has been a gradual shifting of position within some churches. Since 2008, at least on paper, the Catholic Church has been supportive of decriminalisation of homosexual acts.<sup>19</sup> There are of course voices of reason committed to promoting compassionate, evidence-based HIV policies within Islamic communities and within the churches – witness the remarkable leadership of Desmond Tutu on these issues.

It is commendable that Australia is providing funding to the Global Commission on HIV and the Law, along with other national donors, the Ford Foundation and UNDP. In addition to funding, Australia needs to show leadership in advocating support to the Commission’s approach and findings, in advocating for country partners to rely on evidence rather than dogma in their legal and policy responses to HIV, and in engaging with other donors such as the USA on policy implications – such as removal

## THE SPECIAL RAPPORTEUR CALLS UPON STATES:

- (a) To take immediate steps to decriminalize consensual same-sex conduct and to repeal discriminatory laws relating to sexual orientation and gender identity, as well as to implement appropriate awareness-raising interventions on the rights of affected individuals;
- (b) To repeal all laws criminalizing sex work and practices around it, and to establish appropriate regulatory frameworks within which sex workers can enjoy the safe working conditions to which they are entitled. He recommends that States implement programmes and educational initiatives to allow sex workers access to appropriate, quality health services;
- (c) To immediately repeal laws criminalizing the unintentional transmission of or exposure to HIV, and to reconsider the use of specific laws criminalizing intentional transmission of HIV, as domestic laws of the majority of States already contain provisions which allow for prosecution of these exceptional cases;
- (d) To introduce monitoring and accountability mechanisms so as to ensure their obligations to safeguard the enjoyment of the right to health through legislative, judicial and administrative mechanisms, including policies and practices to protect against violations;
- (e) To provide human rights education for health professionals, and to create an environment conducive to collective action and participation.

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This was not an efficacy study, meaning it was not designed to be able to make conclusions about the role of tenofovir in preventing HIV transmission. However, there were data presented on the seroconversions that took place. Overall there were seven such cases: one man tested negative at enrolment but was found to be positive prior to randomisation; three men on placebo seroconverted; and another three men in the delayed arms seroconverted during the nine-month period prior to starting tenofovir or placebo. It is a good sign for the outcome of future efficacy trials that no seroconversions happened while participants were taking tenofovir.

The presentation did not include detailed analysis of the behavioural safety results, but it was clear that unprotected anal intercourse did not increase among study participants, and there was a trend towards decreasing risk behaviours over the course of the study – particularly among men in the immediate tenofovir and placebo arms.

Adherence data on two intermittent PrEP trials (IAVI E001 and E002) from Kenya and Uganda were presented as posters in Vienna. Participants were randomised to one of four arms: daily Truvada or placebo, or intermittent Truvada or placebo (with doses on Mondays and Fridays, and post-coital doses within two hours after sex, not to exceed one dose per day). Adherence rates were significantly higher among discordant couples in both the daily and intermittent arms, compared to female sex workers and men who have sex with men in these same arms. Results also indicated adherence issues for post-coital doses, with self-reports of adherence (including reports at study visits and SMS responses), being much higher than rates suggested by data from MEMS (medication event monitoring systems) which is an electronic pill bottle cap that records when the pill bottle has been opened). Among participants in Kenya the difference was 26% versus almost 100%.

## WHAT NEXT FOR PrEP?

**The iPrEx study is due to report in early 2011. This trial will determine if daily dosing of Truvada is safe and effective in preventing HIV infection in high-risk MSM.**

HPTN 067 (ADAPT Study) is a Phase II study of the use of Intermittent Truvada (daily, vs pre-post, vs bi-weekly), that will start in early 2011 and will include 360 MSM in South Africa and Thailand.

As van Griensven outlined, based on animal models, daily PrEP dosing may not be required.<sup>11</sup> An intermittent dosing strategy is also supported in a recently published article on a study involving men in Thailand by van Griensven and colleagues, which showed that 86% of men had sex on two days per week or less, and 65% reported their last sex to have been planned.<sup>12</sup>

In a subsequent article in *The Lancet*, Willard Cates asked if in fact it is time to change the way biomedical prevention is conceptualised.<sup>13</sup> Currently, interventions are compartmentalised by modes of delivery which has in effect created completely separate fields of research. He proposes the adoption of the generic term ‘pre-exposure prophylaxis’, which could then be broken down by different modes of delivery – oral, topical (vaginal and rectal) and injectable. This would create more collaboration across the microbicide and PrEP fields.

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The implications of HIV on ageing also need serious community engagement. It is hoped the work of GRAI and the output from this research will provide an impetus for action on the part of both the retirement and residential aged-care sector and the GLBTI community.

The culture that exists within the aged-care sector results in a lack of understanding of the social history of GLBTI clients and unique needs of this group. The SwanCare group in Western Australia is the first aged-care provider to commit to adopting the best practice guidelines. Many other aged-care providers appear open and willing to consider how to be more inclusive of GLBTI clients, however they lack the skills to do so. It is time to push forward with quality education and training for this sector.

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UNAIDS Executive Director Michel Sidibé visited China and commended China's response, saying, 'This scale of transformation gives me and many others hope that China can make breathtaking strides in other areas of universal access, if the will is there. And I believe it is.'<sup>17</sup>

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# BOOK REVIEW

## *HIV Treatment and Prevention Technologies in International Perspective*

Reviewed by **Dean Murphy**

This collection of work from several well-known social scientists in the HIV field has its origins in a seminar at the British Sociological Association conference in 2007. It has been produced to overcome what the editors describe as a curious lack of social science engagement with the changing technologies used in the response to the global HIV pandemic.

Given that technologies are the main focus of this book it is important to note that – following the tradition of biological politics – here ‘technologies’ are not just devices and pharmaceuticals but are “hybrid assemblages” ... of knowledges, practices, habits and material resources that have particular effects.’ (p. 10).

The book draws heavily on research in southern Africa and the UK, and to a lesser extent, North America and Australia. The contributors break down many of the binaries that characterise the HIV field, such as treatment/prevention (Mykhalovsky), researchers/researched (Rosengarten and Michael), risk/responsibility (Race), and pre-/post-antiretroviral (ARV) therapy (Davis).

Not surprisingly, many of the chapters focus on HIV prevention in the post-ARV era. Davis, in particular, examines this ‘watershed narrative’, which positions ARV therapy as transforming the epidemic, concluding that this view is dependent on a particular ordering of the relationship between treatment, prevention and ethical citizenship. Prior to the mid-1990s, the absence of treatment gave prevention its ‘value and urgency, but also tied it closely to the failure and success of effective treatment.’ (p. 130). This is seen most starkly in the discourses of disinhibition and treatments optimism found in the post-ARV-therapy era. (It should be noted that this chapter is based on interviews with HIV-positive



gay men in 1999 and 2000, rather than in the more recent era of test and treat policies and the Swiss Consensus Statement).

Additionally, as Paul Flowers argues, the biomedical model has provided a ‘palatable way of engaging with the global epidemic’ (p. 110) that conveniently overlooks the differences in economic and social circumstances. He also examines how this ‘biomedical narrative of HIV’ (and its subsequent normalisation) has overshadowed psychosocial issues (p. 109). Interestingly, stigma surrounding HIV does not seem to have diminished despite treatments advances and a new biomedical understanding of the virus.

The fascinating chapter by Race examines ‘barebacking’ as a technology in its own right. Race makes an interesting comparison between barebacking – as a transgressive attack on ‘good citizenship’, as defined under the imperatives of HIV prevention – and the later discovery and promotion of ‘serosorting’.

Several chapters examine the biopolitics of treatment at a local

or regional level. For example, Eric Mykhalovsky examines the complexity of incorporating prevention within a Canadian organisation that had historically focused on treatments information. Abdullah and Squire also provide an interesting account of scaling up ARV therapy in the Western Cape in South Africa, suggesting that the success of this program is largely due to the new construction of ‘HIV citizenship’ within this province.

The chapter on HIV pre-exposure prophylaxis (PrEP) by Rosengarten and Michael is a highlight. They propose a new way of thinking about PrEP- not as a stable object, distinct from the human and non-human relations that inform it, but instead as ‘processual’, involving the constant working of biological and social phenomena. Their thought-provoking analysis liberates clinical trials from a common conceptualisation as sites of conflict between the researchers and the researched (p. 170), instead presenting them as technologies that bring together people and drugs in particular ways (p. 177).

Although the title of this book may imply that it will cover all new biomedical prevention strategies, circumcision is mentioned only briefly and discussion of HIV vaccine and microbicide development is entirely absent. Overall though, the book is a useful resource, particularly for those interested in thinking about HIV prevention beyond mere viral containment and, instead, as an arrangement of practices, expertise, ethics and apparatuses.

*HIV Treatment and Prevention Technologies in International Perspective*  
Edited by Mark Davis and Corinne Squire  
Published by Palgrave Macmillan, 2010

**Dean Murphy works at AFAO in the areas of HIV education and biomedical prevention.**

By Finn O'Keefe

*thebody.com* is an HIV information website managed by Health Central Network Inc, a New York based organisation that provides medical information through more than 35 different sites, serving over 16 million visitors each month. Their *raison d'être* is to provide access to medical information which can assist people 'to take control of their health and well-being.'<sup>1</sup>

*thebody.com* is Health Central's HIV project, and promotes itself as 'the number one online resource for news and information about HIV/AIDS'.<sup>2</sup> Its four objectives are: to reduce barriers between patients and clinicians; to 'demystify' HIV/AIDS and treatments; to 'improve quality of life' for people living with HIV; and to 'foster community through human connection'.<sup>3</sup> *thebody.com* achieves these objectives admirably and, as a result, is a comprehensive portal to educational material about HIV and other resources for people living with HIV.

The home page includes links to essential HIV information and support materials for those newly diagnosed. Topics include: 'what is HIV?', 'HIV testing 101', 'HIV medications' 'side effects' and 'crazy HIV myths'. These are all housed within the 'just diagnosed resource centre'. The information within this section covers a lot of technical ground, but manages to employ language that remains clear, accessible and friendly throughout. The medical information is balanced by first person narratives from people sharing their experiences of living with HIV. Resources include a photo board which links to people recounting their own stories about coping with positive diagnosis, and their personal perspectives on living with the virus.

Stories are provided using a mixture of text, audio and video. This media-rich experience adds warmth and allows



users to better connect with the stories provided. The multimedia content has the added benefit of providing increased accessibility for those who have difficulty accessing text-based materials. First person narratives are used here to great effect. This keeps the tone direct, reassuring and frank, employing vernacular language.

For instance:

*'Just diagnosed? I would definitely say, first of all, take a deep breath. Don't freak out too much. There's a lot of information out there.'*  
(Jack Mackenroth, New York City, diagnosed in 1990).<sup>4</sup>

The site provides a variety of other resources, including: 'AIDS activist central', which covers global advocacy initiatives; and 'HIV tools you can use', which includes a health tracker where users can track their viral load, CD4 count and other statistics. There is also the facility for site visitors to direct questions to 'leading experts' and to communicate with other users of the site.

An extensive array of breaking HIV news is provided through the 'HIV/AIDS news room'. A prominent rotating banner on the homepage displays four topic areas currently available, illustrating the diversity of issues covered throughout the site. The topics currently highlighted are 'what the heck are microbicides?', 'HIV and Islam' (in the US context), 'men of color' and research presented at 'ICAAC 2010'.

Where *thebody.com* diverts from many other HIV-focused websites, is in its coverage of HIV and the arts. The home page includes a link to a 'Visual

AIDS web gallery' which displays a gorgeous selection of photographic works. These photos may have more to do with artistic expression than health promotion, but the selection provides a strong message of support and empowerment. 'HIV on Screen' is dedicated to promoting films and documentaries that explore HIV-related themes and currently showcases a US-made documentary *The other city*, with a link to the film's trailer and an interview with the filmmakers. These points of difference in the site's focus are refreshing.

One criticism of the site is that while the news it presents is global in its scope, much of the other material on offer is very US-centric. It would be good to see this broadened out to include more coverage of content from outside of the US, thus better catering for the site's presumably large international audience. Overall though, *thebody.com* is an engaging and informative gateway to HIV information, and presents a different range of information to many of its peers.

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## Tenofovir treatment impairs kidney function, but clinical significance limited

Treatment with tenofovir has an adverse impact on kidney function, but the clinical significance of this is modest, according to the results of a systematic review and meta-analysis conducted by an international team of investigators and published in the September 1st edition of *Clinical Infectious Diseases*.

The investigators looked at the results of 17 studies involving a total of 11,000 patients. All the studies compared outcomes in patients taking tenofovir-containing regimens to outcomes observed in patients whose HIV treatment did not include this drug. Loss of kidney function was significantly greater amongst patients who took a combination of drugs that included tenofovir. In addition, those taking tenofovir were more likely to develop kidney disease. However, the investigators comment: 'Although our review identified a significant loss of renal function associated with TDF [tenofovir] use, the clinical magnitude of this effect was modest.'

Tenofovir (*Viread*, also in the combination pills *Truvada* and *Atripla*) is a widely-used antiretroviral drug in both industrialised and resource-limited settings. The clinical trials that formed the basis of the drug's formal approval showed that it was very safe. Nevertheless, after its licensing, case reports were published showing that some patients treated with the drug had developed kidney dysfunction or disease. Moreover, several observational cohort studies have founded that approximately 1% of tenofovir-treated patients per year develop such severe kidney dysfunction that they cease therapy with the drug.

Patients who are taking antiretroviral drugs in the UK and similar countries are recommended to have their kidney function monitored at regular intervals. However, such monitoring is impractical and unaffordable in many poorer countries. Therefore, to gain a better understanding of the safety of treatment with tenofovir investigators performed a systematic review and meta-analysis of studies reporting on kidney function in patients taking the drug. They also monitored the effect of the drug on bone metabolism, as there is some evidence that therapy with tenofovir may reduce bone mineral density and increase the risk of fractures.

A total of 17 studies were identified by the investigators. The design of these studies varied. Nine were randomised controlled trials, five of which were double-blinded. Seven studies gathered prospective, observational data, and one study used prospectively collected information from an adverse events register.

A total of 10,889 patients were recruited to these studies. The individual sample sizes ranged from 49 to 3439. The median duration of follow-up was 48 weeks.

Randomised controlled trials were more likely to find that tenofovir had an adverse impact on kidney function. There was some evidence that patients who had experience of antiretroviral therapy were more likely to experience a loss of kidney function due to tenofovir treatment, compared to patients starting antiretroviral drugs for the first time.

Studies that were sponsored by drug companies were slightly less likely to find an association between tenofovir treatment and loss of kidney function than was research funded from other sources.

Eight studies reported on the incidence of kidney disease. There was a small, but significant, increase in the risk of acute renal failure for patients taking tenofovir (difference with patients taking an alternative antiretroviral = 0.7%).

However, treatment with tenofovir was not associated with any increase in the risk of chronic kidney disease, or of end-stage kidney failure requiring long-term dialysis. Nor were patients taking tenofovir more likely to have protein in their urine.

'Our systematic review suggests that the risk of clinically relevant renal toxicity due to TDF is relatively low, at least during the short-term', the investigators note. Nevertheless, they note that dozens of cases of tenofovir-associated kidney dysfunction have been reported. The researchers provide a number of explanations for the differences between the findings of their meta-analysis and the outcomes seen in routine practice:

- More sensitive testing of kidney function was used to diagnose the cases seen in 'real world' settings.
- Many of the cases seen in clinical practice involved individuals who were also taking ddi (didanosine, *Videx*, *Videx EC*) or a ritonavir-boosted protease inhibitor. By contrast, most of the patients in the studies were taking an NNRTI and the use of ddi was scrupulously avoided.
- Many case reports involve older patients, those with advanced HIV disease, and individuals with mild kidney dysfunction at baseline. Such individuals would be excluded from clinical trials.

'Our findings do not support the need to restrict TDF use in jurisdictions where regular monitoring of renal function ... is difficult or impractical', conclude the investigators.

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— Michael Carter, *Aidsmap*

*continued overleaf*

## People with HIV with higher CD4 counts should not miss seasonal flu jabs

**H**IV-positive patients with a CD4 cell count below 350 cells/mm<sup>3</sup> have an impaired immune response to the seasonal influenza (flu) vaccine, Swiss investigators report in the September 10th edition of *AIDS*. They recommend that all HIV-positive patients should have an annual influenza vaccine to help them to establish flu-specific memory immune cells, the formation of which can be difficult after the immune system suffers serious damage.

The study was undertaken because investigators from Basel wished to assess responses to the seasonal influenza vaccine in HIV-positive patients. Blood samples were therefore taken from 24 HIV-positive patients and 31 HIV-negative controls immediately before administration of the seasonal flu vaccine in 2007–2008, and again approximately 30 days later. The production of two forms of influenza antibodies – IgM and IgG – and levels of flu-specific CD4 cells were measured.

All the HIV-positive patients had been taking antiretroviral therapy for at least three months and had a viral load below 200 copies/ml.

In HIV-negative individuals, median levels of influenza-specific IgM and IgG increased significantly after the receipt of the vaccine. In addition,

increases in influenza-specific CD4 cell counts were observed in 92% of individuals.

Amongst HIV-positive patients with well-preserved immunity (a CD4 cell count above 350 cells/mm<sup>3</sup>), the administration of the vaccine led to significant increases in levels of flu-specific IgM and IgG. However, only 64% of patients had an increase in their flu-specific CD4 cell count.

A poor response to the vaccine was seen in the HIV-positive patients whose CD4 cell count was below 350 cells/mm<sup>3</sup>. No significant increase in influenza-specific IgM antibody levels were seen, and only two patients had any IgM response at all. Moreover, only 44% of patients had an increase in their influenza-specific CD4 cell count. However, a significant increase in levels of post-vaccination influenza-specific IgG was observed.

‘Increasing levels of IgG in this study group most likely reflects a memory response’, comment the investigators. They believe that this finding is important and ‘provides an immunologic rationale supporting the recommendation of annual influenza vaccinations throughout the course of HIV infection.’

Such vaccinations when a patient’s immune system is intact build up ‘broad and long-lasting’ B-cell memory.

The importance of such memory cells was shown in the recent H1N1 pandemic. Children were especially

vulnerable to this strain of flu because they lacked the protective antibodies that are developed from contact with earlier strains of flu.

‘These preliminary data should trigger future research aiming to understand the molecular basis of the observed lack of IgM-production’, recommend the investigators.

The findings of the study also have significance for clinical practice as they ‘lend support to strictly enacting annual influenza-vaccination in all HIV-infected individuals regardless of their CD4+ T-cell count.’

These findings, which broadly correspond with findings from a sample of US patients showing that lack of response to H1N1 vaccine was associated with a low CD4 count, suggest that people with HIV with higher CD4 counts may derive the greatest benefit from current influenza vaccines, and that more research is needed to determine how to improve influenza vaccine responses in people with low CD4 counts.

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— Michael Carter, *Aidsmap*

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18–20

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20–22

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### November

4–6

#### **12th International Workshop on Adverse Drug Reactions and Co-Morbidities in HIV**

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7–9

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17–18

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### January 2011

10–11

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19–21

#### **14th Bangkok International Symposium on HIV Medicine**

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### February

5–6

#### **India – International Pediatric AIDS Conference**

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20–25

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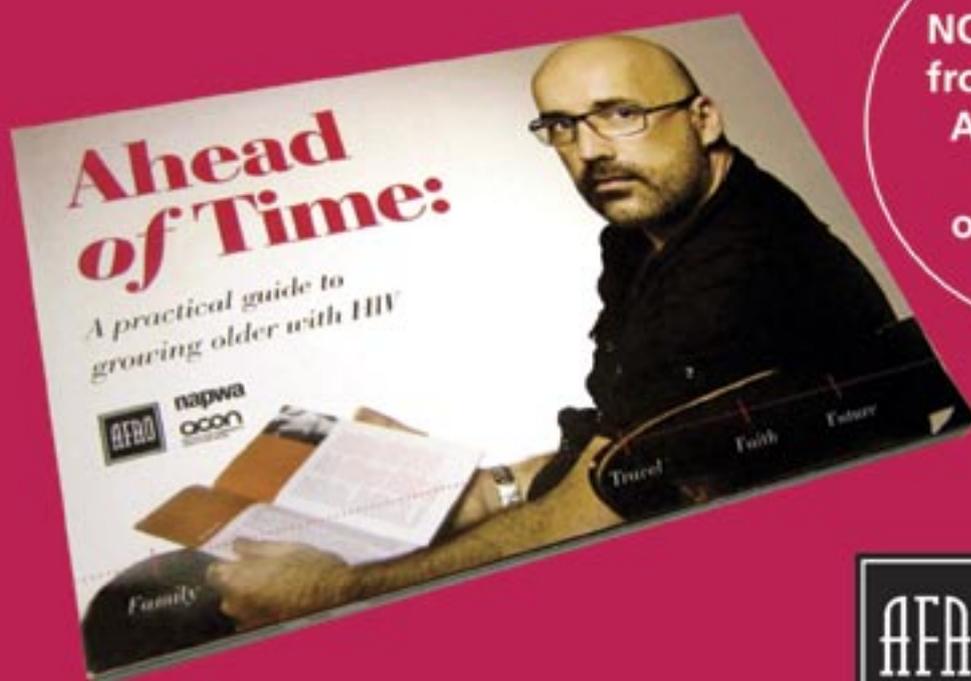
# Diary

# Ahead of Time:

*A practical guide to growing older with HIV*

This booklet is specifically designed to help people living with HIV make the best decisions about their health as they begin to grow older.

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