

# HIV AUSTRALIA



HIV and  
relationships

Volume 12 • Number 1

24 COURSE DE VÉLO D'HEURE

Red sleeveless top

Red and white striped t-shirt with text:  
SINCE 1969  
We've got the gear  
made in all

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

AFAO's aims are to:

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

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This edition of *HIV Australia* focuses on HIV and relationships. Contributors discuss research, and present personal and historical accounts about their own and others' lived experiences.

A broad spectrum of relationships are discussed, including sexual and platonic relationships, relationships with friends, family and peers, and relationships involving organisations and community.

Cover image and images on pages 7, 12 and 35:  
**John McRae** – [www.johnmcrac.com](http://www.johnmcrac.com)

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



## NEWS

### AUSTRALIA

#### Major barrier to treatment access removed

In December, the Pharmaceutical Benefits Advisory Committee (PBAC) announced the removal of a major regulatory barrier preventing some people from starting HIV treatment early.

Previous prescribing restrictions meant that HIV-positive people who had CD4 count of 500 cells/mm<sup>3</sup> or above and were asymptomatic were prevented from accessing treatments through the pharmaceutical benefits scheme (PBS). The removal of this regulatory barrier gives HIV-positive people the option of commencing treatment when they choose to do so.

The decision was made in response to a joint submission from the National Association of People with HIV Australia (NAPWHA), the Australasian Society for HIV Medicine (ASHM) and the Australian Federation of AIDS Organisations (AFAO), with assistance from the Kirby Institute. The amendment has been hailed as a major step forward in the fight against HIV in Australia.

'This restriction made no sense in this modern era of HIV treatment. Today, leading guidelines and many expert clinicians recommend people with HIV consider starting treatment earlier to benefit their health and wellbeing,' said spokesperson for NAPWHA, Bill Whittaker.

Associate Professor Edwina Wright, President of ASHM, who chaired the submission, said that HIV-positive people may now decide commence to treatment for a variety of reasons.

'We are pleased with the PBAC's decision, as now all HIV-positive people in Australia can access antiretroviral therapy.

'This includes HIV-positive people who are well and have high CD4 cell counts, but who may wish to commence therapy based on their confidence in the current level of evidence and/or their wish to minimise their risk of transmission to others,' A/Prof Wright said.

It is estimated that around 200 patients each year will benefit from the PBAC decision.

#### Sexual-activity-based deferrals for blood donation remain unchanged

The Therapeutic Goods Administration (TGA) has rejected an application to reduce the blood donation deferral period for gay and bisexual men from 12 months to 6 months. The TGA announced the decision on 1 January 2014.

Following recommendations made by an expert review committee convened by The Red Cross Blood Service in 2011, an application was made to the TGA to reduce the donor deferral period for some sexual activity.

The TGA rejected the application on the basis that reducing the deferral period could increase the risk of an infection being passed on to a blood recipient with no significant boost to donor numbers, or to the blood supply. Blood Service Chief Executive, Jennifer Williams, said the Blood Service accepted the TGA's decision but was disappointed.

AFAO Executive Director Rob Lake, who was a member of the Red Cross review committee, said that the application to reduce the deferral period was based on sound evidence, and that many gay and bisexual men experienced this deferral as a form of discrimination.

'Often, gay men who are refused the opportunity to donate blood are confused or shocked at the automatic exclusion they face for making what is a community minded decision,' Mr Lake said.

He said that AFAO will continue to work with the Red Cross Blood Service on how they communicate with gay

men about this policy while continuing to advocate for its change.

'We, along with the Red Cross, believe that the evidence supporting the deferral reduction is growing and will continue to pursue the reduction,' Mr Lake said.

#### HIV response pioneer receives Australia Day honour

HIV/AIDS response pioneer Don Baxter AO was appointed a Member of the Order of Australia on Australia Day 2014, in recognition of the major role he has played in leading Australia's response to HIV.

AFAO Executive Director Rob Lake welcomed the appointment, describing it as incredibly well deserved. 'Australia's initial response to the AIDS crisis in the 1980s is rightly acknowledged today as a global benchmark – and Don was a key driver of that,' Mr Lake said.

Mr Lake noted Mr Baxter's tireless work since the beginning of the epidemic and the key role he has played more recently in the global fight against HIV and AIDS, in helping to establish the Global Forum on MSM and HIV and since 2011, acting as a Board member of the Global Fund on AIDS, TB and Malaria.

Other Honours awarded on the day included Professor Rob Moodie AM and Professor Michael Matthew Daube AO.

Professor Moodie received a Medal of the Order of Australia (AM) for significant service to medicine through HIV/AIDS research, and through leadership roles in population health and disease prevention programs. Professor Daube was awarded the Officer of the Order of Australia (AO) in the general division for distinguished service to medicine, particularly in the area of public health policy and reform, through advisory roles with leading national and international organisations, and to youth.

#### Leading HIV expert to head new research centre in Victoria

Internationally renowned HIV and infectious disease expert, Professor Sharon Lewin, has been appointed the inaugural Director of the Peter Doherty Institute for Infection and Immunity at the University of Melbourne.

The Peter Doherty Institute is a \$210 million world-class research centre which is scheduled to open later this year. The Institute, the result of a partnership between Melbourne Health and the University of Melbourne, will house around 700 expert scientists, researchers, clinicians, academics, staff and students focusing on infectious human diseases.

Professor Doherty, Patron of the new Institute, described Professor Lewin as one of the leading minds in Australia.

'Professor Lewin is dedicated to understanding infectious diseases and the immune system. She is a world leader on conditions such as HIV and hepatitis B and her vision will make a difference to the conquest of disease,' said Professor Doherty.

Professor Lewin is a member of the International AIDS Society (IAS) international working group currently developing a global scientific strategy for HIV cure research, and is co-chair of the upcoming International AIDS Conference (AIDS 2014). She is also a current member of the Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmitted Infections, the peak advisory body to the Australian government on blood borne viruses.

Professor Lewin currently heads the Department of Infectious Diseases, Alfred Health and Monash University and is co-head of the Centre for Biomedical Research, Burnet Institute. She is expected to begin her directorship of the Doherty in September 2014.

### **ACON puts focus on HIV testing**

**A**CON has launched Test More – the third phase of the Ending HIV campaign – alongside a pop-up rapid testing site operating on Oxford St in Sydney until 21 March.

The Ending HIV campaign aims to inform gay men about action they can take to help eliminate the transmission of the HIV virus in NSW by 2020. ACON President Mark Orr says increasing testing rates among gay men is vital to ACON's Ending HIV strategy. 'We estimate that up to 30% of HIV cases in NSW are undiagnosed and it's these people, who are unaware of their status, who we particularly want to work with,' Mr Orr says.

'Once people know their status, they can take action to improve their health outcomes and prevent passing on the virus. And the only way they can know their status is to get tested regularly, at least twice a year.'

A key part of ACON's strategy is to increase testing rates in NSW through its community-based a[TEST] rapid testing clinics, where gay men can receive an HIV rapid test results in 30 minutes.

Rapid testing is currently available in three states: New South Wales, Victoria and Queensland. Rapid testing sites operating outside of NSW – including 'PRONTO!' in Melbourne and 'Testing Point' in Queensland – are also reporting strong attendance. For site locations around the country or to book a test, visit [www.endinghiv.org.au](http://www.endinghiv.org.au)

AFAO is coordinating a national rollout of the Ending HIV campaign in other states and territories through its member organisations.

### **PrEP most cost effective for gay men in serodiscordant relationships**

**R**esearch examining the cost-effectiveness and population-level impact of pre-exposure prophylaxis (PrEP) as a public health intervention concluded that PrEP is most cost effective in an Australian context when targeted to men in serodiscordant relationships.

The study, published in *Clinical Infectious Diseases* in January, used modelling to predict clinical and cost outcomes of providing PrEP to MSM in New South Wales. Outcomes were reported as incremental cost effectiveness ratios (ICERs) in 2013 Australian dollars per quality-adjusted life year gained (QALYG).

Scenarios used in the study included prioritising PrEP to 10–30% of the general MSM population, 15–30% of MSM with more than 10–50 sexual partners per six months, and 15–30% of HIV-negative MSM in discordant regular partnerships.

The use of PrEP in 10–30% of all gay men in NSW was projected to cost \$316–952 million dollars over 10 years, and cost more than \$400,000 per QALYG. The study authors commented

that providing PrEP to this proportion of men was not cost-effective, and also said that achieving such high rates of coverage was likely to be quite unrealistic.

If MSM with more than 10 partners and MSM with more than 50 partners over a six month period were targeted, the cost would be \$31 million to \$331 million over 10 years, amounting to more than \$110,000 per QALYG.

Results showed improved cost-effectiveness when targeting specific groups of men at high risk of acquiring HIV. The most cost-effective of these involved targeting HIV-negative men in a discordant regular partnership; ICERs ranged between \$8,399 and \$11,575 per QALYG for coverage ranging between 15% and 30%.

The study suggests that use of PrEP to reduce the incidence of HIV among gay men in Australia is cost effective when targeted to specific groups, although this would not have a large population-level impact. However, none of scenarios in the model included current condom use in determining subgroups of gay men for whom PrEP might be cost effective, although, interestingly, reductions in condom use with male partners due to PrEP of between 25%–75% were used in the sensitivity analysis.

'The results show that PrEP should not be used widely, and is only potentially cost-effective for certain people, primarily HIV-negative MSM in discordant couples where the HIV-positive individual does not take antiretroviral therapy and the couple do not use condoms,' David Wilson, one of the study authors, told *Infectious Disease News*. 'PrEP could be used more broadly only if drug companies would be willing to reduce the price of the drugs.' Changes to the cost of drugs would affect the assumptions on which cost-effectiveness decisions are made.

## **INTERNATIONAL**

### **UN says new anti-homosexuality law in Uganda violates human rights**

**U**nited Nations Secretary-General Ban Ki-Moon and United Nations High Commissioner for Human

*continued overleaf*

Rights Navi Pillay have condemned the anti-homosexuality law brought into force in Uganda on 14 February, saying it will violate basic human rights, and endanger the lives of lesbian, gay, bisexual and transgender (LGBT) people in Uganda.

Mr Ban's spokesperson, Martin Neskirky, said that the Secretary-General is 'seriously concerned' about the negative impact of the new law and shares the High Commissioner's view that it violates human rights.

'It will institutionalise discrimination, restrict the vital work of human rights activists, and could trigger violence. It will also hamper potentially life-saving efforts to stop the spread of HIV,' Martin Neskirky told reporters in New York.

Under the new law, the penalty for same-sex conduct is now life imprisonment. The 'attempt to commit homosexuality' incurs a penalty of seven years, as does 'aiding and abetting' homosexuality. A person who 'keeps a house, room, set of rooms, or place of any kind for purposes of homosexuality' also faces seven years' imprisonment.

Ms Pillay stressed that Uganda is obliged, both by its own Constitution and by international law, to respect the rights of all individuals and to protect them from discrimination and violence.

'This law violates a host of fundamental human rights, including the right to freedom from discrimination, to privacy, freedom of association, peaceful assembly, opinion and expression and equality before the law – all of which are enshrined in Uganda's own Constitution and in the international treaties it has ratified,' Ms Pillay said.

Meanwhile, In Australia, the Australian Greens have called on Prime Minister Tony Abbott to join with other international leaders in condemning the new laws.

'Tony Abbott has a moral obligation to condemn these horrific laws and to work with the global community to guarantee the safety of all those named as LGBTI in the Ugandan tabloid Red Pepper,' Greens Leader Christine Milne said. 'If applications for asylum are received from any of the named

200 or others at risk Tony Abbott must guarantee their safety and provide permanent protection immediately.'

### **Nigeria passes draconian law banning same-sex relationships**

The United Nations Human Rights Chief has voiced alarm at a 'draconian' new law in Nigeria that further criminalises lesbian, gay, bisexual and transgender (LGBT) people, organisations and activities, as well as people who support them.

Under a new law signed by Nigerian President Goodluck Jonathan in January, it is illegal not only to engage in an intimate relationship with a member of the same sex, but to attend or organise a meeting of gays, or patronise or operate any type of gay organisation, including private clubs.

'Rarely have I seen a piece of legislation that in so few paragraphs directly violates so many basic, universal human rights,' said High Commissioner for Human Rights Navi Pillay.

The Act includes a provision for a 14-year prison term for anyone who enters into a same-sex union, and a 10-year prison term for anyone who 'administers, witnesses, abets or aids' a same-sex marriage or civil union ceremony. Even before this Act was signed into law, consensual same sex relationships were already criminalised in Nigeria.

Amnesty International reports that since the passing of this law, there has been an upsurge in arrests of LGBT Nigerians, including at least five allegedly gay men in Ibadan, Oyo state.

UNAIDS has also expressed grave concerns that the new law could prevent LGBT people from accessing essential HIV services.

'The provisions of the new law in Nigeria could lead to increased homophobia, discrimination, denial of HIV services and violence based on real or perceived sexual orientation and gender identity,' noted UNAIDS Executive Director Michel Sidibé. 'It could also be used against organisations working to provide HIV prevention and treatment services to LGBT people.'

## **ASIA PACIFIC**

### **Transgender activists in Asia and the Pacific highlight HIV and other health issues**

A regional meeting held in Bangkok in late February, saw transgender activists meet with leading health experts for the first time to discuss transgender health issues and latest advances in research and advocacy for transgender people. Community representatives at the World Professional Association for Transgender Health (WPATH) symposium highlighted how transgender women and men routinely experience discrimination and violence, saying that this creates barriers for effective responses to HIV/AIDS.

Joe Wong, spokesman for the Fronting Trans Movement in Singapore, told the Australia News Network that transgender men are among the most neglected and invisible groups in society. He explained that many trans men are prevented from accessing HIV testing or treatment due to stigma and discrimination.

'There is no existence of any HIV services available for trans men; there's no access to prevention brochures, no access to prevention messages and there is just no healthcare providers who are sensitised enough to talk about such issues... There is still not much acceptance within the community that gay transmen do exist,' Mr Wong said.

Laxmi Narayan Tripathi, a *Hijra* activist who was the first transgender person to represent Asia-Pacific in the UN General Assembly task force on HIV/AIDS, said that the symposium provided a unique opportunity to initiate a dialogue about transgender issues with the scientific and medical community.

'It is very useful... that for the first time, the community is involved in this quite technical group of scientists and doctors who are this WPATH.' She explained that although the *Hijra* community still faces discrimination in India, the situation is improving. 'In our passport, we can choose our sex and in the identity card, we have "transgender".'



## Building intimacy, managing risk: gay men's relationships and HIV

By **Ian Down**

According to Gay Community Periodic Survey data, about 60% of Australian gay men are in regular relationships.<sup>1</sup> Since the beginning of the HIV epidemic, gay men have often found intimacy through their relationships while also managing risk of HIV transmission within those relationships, especially through 'negotiated safety' whereby HIV-negative men in committed relationships agree to forego condoms with each other while continuing to practise safe sex with all other partners.<sup>2</sup> Negotiated safety, applied consistently, can substantially protect men from acquiring HIV.<sup>3</sup>

The first Australian study of recently HIV-diagnosed gay men, which collected data from 1993–2001, found that 42% had become HIV-positive as a result of sex with a regular partner.<sup>4</sup> Of the men interviewed during the PHAEDRA study from 2003–2004, 29% reported having acquired HIV through sex with their regular partner.<sup>5</sup> It is possible that this apparent reduction in proportion of infections between regular partners could be attributed to the success of promoting negotiated safety agreements through the 'Talk, Test, Test, Trust' campaign, initiated by ACON in 1996. However, while currently about three quarters of regular relationships are between men who are

seroconcordant (where both partners are of the same HIV status), the proportion of HIV-negative men with a negotiated safety agreement has been falling over the years, from about 70% in 2007 to just below 30% in 2012.<sup>6</sup>

Negotiated safety has remained a component of many peer education workshops, and there has been an increased, and much needed, focus on men in committed serodiscordant relationships (where partners have mixed HIV status). However, over the past decade there has been less attention paid to reminding men of the necessary components required to implement relationship agreements successfully, including on how men can manage HIV risk within the broad range of relationship styles found among gay men.<sup>7</sup>

### The HIV Seroconversion Study

The Seroconversion Study collects data from people in Australia recently diagnosed with HIV, to help understand the factors associated with recent HIV infection, and learn about the experiences of being recently diagnosed with HIV. The current version of the study began in 2007. Since then, 506 gay and bisexual men have completed the online survey, 95 of whom were also

interviewed. Participants are asked about their relationships at the time of the high-risk event they believe led to their seroconversion, and about their relationship with the person from whom they believe they acquired their infection. More recently, we have begun asking about the nature of the participant's relationships since their diagnosis.

### Men's relationships at time of the high-risk event

Less than a third (30%) of the gay and bisexual men in the current Seroconversion Study reported that they had a regular male partner at the time of their high-risk event. While more than half these relationships were of more than two years duration, a significant proportion, one in five, were of less than six months duration. Most (84%) of the men in regular relationships knew the HIV status of their partner at the time of the high-risk event; 70% believed that partner to be HIV-negative, while 14% believed them to be HIV-positive. Still, one in six did not know their partner's status at that time. About half the gay and bisexual men with regular partners engaged in receptive unprotected anal

*continued overleaf*

intercourse (UAI) with their partner during the six months prior to their diagnosis, regardless of that partner's HIV status, while one in three engaged in insertive UAI with those partners.

Of the gay and bisexual men in a regular relationship at the time of the high-risk event, more than half reported having more than one regular partner, such as a 'fuckbuddy', in the six months prior to testing HIV-positive; the average number of other regular partners was four. About a quarter of men with regular male partners also engaged in receptive UAI with casual partners, while one in five engaged in insertive UAI with casual partners.

### Relationship to source person

In the current version of the study, gay and bisexual men are asked to distinguish between regular male partners they considered to be their primary partner, or 'boyfriend', and regular male sex partners they considered to be 'fuckbuddies' or 'friends with benefits'. Just 11% of men reported sex with their boyfriend on the occasion they believe they acquired HIV, 23% indicated it was through sex with a fuckbuddy, while for the majority (61%) this was through sex with a casual male partner.

When compared with those men who acquired HIV from their boyfriend, men who believed that they had contracted HIV from a fuckbuddy were less likely to describe that person as someone they knew well (34% versus 79%), and were more likely not to know the HIV status of that partner (40% versus 9%). Only 6% reported that the source person was a boyfriend of more than three months standing. Among the men in the sample who reported that the source person was a casual partner, almost a third (31%) reported

some prior acquaintance with that partner, and one in five (21%) reported having had sex with them on a previous occasion – almost three quarters of whom had had sex with them on more than one previous occasion.

In interviews, men described a desire for intimacy and connection in situations where there was an ongoing acquaintance with the partner considered to be the source person. This was usually expressed as a connection with someone they felt they knew or could trust and with whom they wanted to share a close sense of intimacy.

### Building capacity to reduce HIV transmission in relationships

Few gay men appear to acquire HIV from long-term committed regular partners. Tools to assist gay men in negotiating agreements in short-term and non-committed relationships may assist in HIV prevention. Health promotion initiatives that portray gay men's relationships, particularly relatively short-term sexual relationships – whether they are with an acknowledged regular partner or a relatively new friendship or other acquaintance that includes a sexual component – may help reduce HIV transmissions within these kinds of partnerships. Additionally, it would be useful to consider the implications of issues of trust, and what resources might be provided to enable individuals to make decisions about risk behaviour that might assist men to distinguish when and under what circumstances this trust can be considered reliable. Skills to help men negotiate agreements with multiple regular sex partners, and to communicate when agreements break down could further help. Pre-exposure prophylaxis (PrEP) may also offer an appropriate alternative option for some men in these situations.

***The Seroconversion Study continues to recruit people in Australia recently diagnosed with HIV. Anyone who has been diagnosed as HIV-positive in the past two years can join the study at [www.hivss.net](http://www.hivss.net). The 2013 study report is now available to download from the study website. For further information, please contact Ian Down on (02) 9385 9954 or at [idown@kirby.unsw.edu.au](mailto:idown@kirby.unsw.edu.au).***

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## A note to our readers

**In most Australian states and territories, public health legislation stipulates that people with HIV must take reasonable precautions or measures to prevent transmission of HIV to sexual partners. Using reasonable precautions is likely to be the best defence to any criminal charge.**

Articles in this edition of *HIV Australia* discuss a range of risk reduction strategies that may prevent sexual transmission of HIV – including negotiated safety, 'treatment as prevention', and use of pre-exposure prophylaxis (PrEP). These strategies are not explicitly named and have not been tested under Australian law, so relying on them during sexual encounters leaves individuals at risk of prosecution, particularly if they have not disclosed HIV-positive status.

Whether you are HIV-positive or negative and you are having penetrative anal sex (receptive or insertive) or vaginal sex, using condoms and a water-based or silicon-based lube is the most effective way to prevent sexual transmission of HIV.

# Our Team: a new relationship resource for gay men

By **Dean Murphy**

AFAO's health promotion program has just launched a new booklet called *Our Team: A Guide to Negotiating Relationships for Gay Men*. This represents an important new addition to materials on this subject. The primary target audience for the resource is gay men in the early stages of relationships, particularly younger gay men.

Steady relationships form an important feature of gay men's kinship practices. Around 55–60% of gay men surveyed in gay communities in Australian cities reported that they are currently in a relationship and this proportion has remained stable over time.<sup>1</sup> Of the men in relationships, half reported that they also have sex with casual sex partners. Almost one-third of relationships are less than one year old, which suggests a reasonably high proportion of relationship turnover.<sup>2</sup> However, another recent national cross sectional survey of gay men found that a quarter of men in relationships had been with the same partner for more than ten years.<sup>3</sup>

In terms of sexual practices, it is quite common for men in relationships to report that they do not use condoms for sex with their partner. In fact around half of men in relationships report not using condoms, and this proportion has also remained stable over time. Not surprisingly, unprotected sex was much more likely among men in relationships with someone of the same HIV status. Despite overall trends in relationships remaining quite stable, there have been some changes in the last few years, mainly related to patterns of HIV status and sexual agreements. Recent surveys of gay men have indicated that HIV-negative seroconcordant relationships (where both partners are HIV-negative) have generally become much more likely over time and serodiscordant relationships have become less likely. This suggests a greater focus on HIV-negative men knowing each other's HIV status and finding a same-status partner.



Sexual agreements related to reducing HIV risk were first identified in gay men's relationships in the early 1990s, specifically 'negotiated safety' agreements between HIV-negative men. These are explicit agreements to limit unprotected sex to the relationship and for all sex with casual partners to exclude anal sex or to always include condoms. Agreements include understandings about sex within the relationship and with outside partners. Negotiated safety agreements have become less common over time in all jurisdictions.<sup>4</sup>

## Resource development

AFAO organised a national meeting of experts (including people working in health promotion, campaign development, peer education, counselling and research) to discuss the needs of gay men and relationship agreements, in order to develop the content for the relationship resource. The experts reviewed the available literature and previous campaign/education materials, and drew on their own experience with clients and gay community to develop key themes to be covered in the resource. These were: relationship aspirations and dynamics; agreements; and communication.

The identification of these themes suggested the need for a resource that assisted men – especially those early in relationships – with developing negotiated safety agreements. The booklet utilises sport metaphors to emphasise the concepts of play, teamwork and youth. The booklet is packaged inside a fold-out sleeve that serves as a relationship agreement worksheet.

***The 'Our Team' booklet is available from venues, clinics and your local AIDS Council.***

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# Moving beyond 'risk' and 'difference': understanding the dynamics of serodiscordant relationships

By **Asha Persson** and **Jeanne Ellard**

Relationships between partners with mixed HIV status (serodiscordance) exist wherever the epidemic exists, and are seen as a major context in which HIV transmission occurs in many parts of the world. As a result, 'risk' has become a key focus in prevention research on serodiscordant relationships. Much of this research is informed by an assumption that serodiscordant partners always perceive and experience their respective serostatus in terms of their 'difference' from one another, a difference that they recognise as a distinctive sexual 'risk', which they are deemed to manage competently or not.

But even though surveys and trials investigating sexual behaviour and HIV transmission among serodiscordant couples have burgeoned in recent years, they shed little light on how couples themselves perceive their relationship and sexual practices, or whether HIV 'risk' might be understood in ways that differ from that of epidemiologists, prevention experts, or social scientists.

The notion that serodiscordant relationships are inevitably defined by 'difference' and 'risk' is challenged by a

small but growing body of studies from different parts of the world that show how serodiscordance can encompass a range of local meanings and practices that far exceed any simple or unitary definition.<sup>1</sup>

To understand the dynamics of serodiscordance, there is a need to move beyond the idea of 'risk' as an objective fact, and instead examine what HIV 'risk' actually means in different cultures and contexts, and how serodiscordance is shaped in many and varied ways by gender, sexuality, medicine, relationship priorities, competing logics, community attitudes, and the dynamics of local epidemics. It is within these contexts that perceptions and negotiations of HIV risk arise and, therefore, where couples' sexual practices need to be situated and understood.

Such insights are timely as the international HIV community grapple with emerging scientific data on the preventative effects of antiretroviral treatment, which are challenging and changing long-held understandings about HIV transmission risk. How might the global push for treatment as prevention (TasP) give rise to new

forms of intimacy and prevention among couples in different cultural settings? NSW provides a good case study, with TasP being a central component of its new HIV Strategy<sup>2</sup> and Ending HIV campaign<sup>3</sup>.

In partnership with several research centres and community HIV organisations, the Centre for Social Research in Health (UNSW) is currently conducting a qualitative study in NSW on the social, sexual, emotional and medical management of HIV among serodiscordant couples in a changing epidemic: YouMe&HIV.<sup>4</sup>

Preliminary findings from this study suggest that, for many of the 29 participants interviewed so far, treatment is a key issue for people in serodiscordant relationships; it enables a sense of sexual safety, and thereby, a sense of possibility.

*There just seems to be this movement towards it now, which is awesome, you know, it's great. So it's just ... opened my eyes to a whole new world, really. And I guess I've been living in a fairly limited view of how all this had to work for me and now I just feel freer ... I can actually love who I love,*

rather than be limited to, you know, 'Are you positive or not?' Yeah, that's big. – HIV-positive gay man

*I can speak as a positive person, the fear of infecting someone else is just overwhelming, especially somebody you love. And so, you know ... [TasP] would help you to be able to relax and enjoy your sex life, enjoy your relationship with your partner. It's one less thing to worry about.*  
– HIV-positive heterosexual woman

Nearly all HIV-positive partners interviewed so far are on effective treatment, and both positive and negative partners are overwhelmingly positive about the mounting research and growing global consensus on HIV treatments as a prevention tool. Yet there are a range of perspectives on HIV risk, as suggested by three themes emerging in the interviews:

TasP provides 'an extra layer of protection' alongside ongoing commitment to condom use, as it is not safe enough on its own:

*I think the treatments should commence sooner rather than later ... [The possibility of unprotected sex because of TasP] flew through my mind once and I thought "no, the last thing I'd ever want to do is have something go wrong and him get HIV". I couldn't do that to him. I love him too much. And that was the end of that argument. I'm not willing to risk it. And condoms are the best method of prevention still today.*  
– HIV-positive gay man

Growing recognition of TasP provides 'welcome relief, reassurance or validation' for those who already practise unprotected sex:

*[Unprotected sex] was very scary at first but, you know, it's something that has to be negotiated as a couple ... But now having seen the release of the [NSW HIV Strategy<sup>5</sup>] and understanding that this is, you know, a common consensus ... that this is a positive move to take a step further to stopping HIV ... it's taken that uncomfortableness away, that fear away ... I think that I can safely say that my partner and I believe*

*that safe sex now ... is having an undetectable viral load on its own.*  
– HIV-positive heterosexual woman

For those who dislike condoms or experience latex-sensitivity, TasP provides 'permission to consider unprotected sex':

*And then that study [HPTN 052<sup>6</sup>] came out ... So then we were like relieved, really, and able to kind of go ahead [and have unprotected sex] ... And make a decision ... I could sit there and go, "These are the facts. If he has his medication every day, which, by evidence, he's doing that every day, I'm willing to take the risk because I know he's doing everything he possibly can to keep me safe.*  
– HIV-negative trans man

For many participants, the notions of 'risk' and 'difference' are at the heart of what they see as significant stigma around serodiscordant relationships and the so called 'sero-divide' in affected communities. However, many negative partners emphasise that there is safety in 'knowing what you're dealing with':

*I'm safer with [partner] because I know it and I can face it head on, and do something about it rather than thinking that someone is negative and being at total risk. So there is that. So it's a really good attribute that, you know, it's there. Face it!*  
– HIV-negative gay man

While many couples simply 'get on with it', a serodiscordant relationship is by no means without its challenges, as participants make clear. A number of issues and decisions can be at stake, including sexual safety, monogamy or open relationships, reproduction, treatment, testing, and disclosure to others. But preliminary findings suggest that the emotional work and honest communication that might be required by couples to tackle those challenges can bring about considerable closeness and sincerity in the relationship.

*It's a really conscious relationship in terms of communication, feelings, care, nurture, protection. It's just all that stuff. It's really, yeah, I guess [serodiscordance]'s been the platform for all of that stuff to really come to the fore. – HIV-negative gay man*

Although HIV figures in diverse and sometimes complex ways in these relationships, the participants we have interviewed so far are not necessarily defined by 'risk' and 'difference', as is often assumed. The picture of serodiscordant relationships emerging in the study is one of considerable emotional intimacy, characterised by both partners' deep commitment to care for each other's wellbeing. At the same time, it is clear that serodiscordance is managed in very different ways and shaped by varied circumstances among the couples. This will be explored in detail during the study to increase understanding about the needs and experiences of these couples and to 'put them on the map'.

***If you'd like more information or participate in a confidential interview, contact Asha on (02) 9385 6414 or a.persson@unsw.edu.au, or visit: <http://csrh.org/youmeandhiv>***

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## Gay men's relationships and kinship

By **Dean Murphy**

Research on gay male relationships has been dominated by questions of HIV risk – both inside and outside the relationship. What has been often overlooked are gay men's aspirations in terms of sexual and romantic relationships, and how these have changed over time (both generationally and within individuals). This article undertakes a brief overview of some of the research on gay men's relationships. Also, I comment on the emerging body of work on gay male parenthood, which is evidence of a renewed research interest in gay male kinship, and has occurred in parallel with the demand for the recognition of same-sex relationships by the state.

### Relationship styles

Research on gay men's relationships conducted in the 1970s and 1980s, illustrates a great interest in relationship styles. This research identified a number of 'regulatory mechanisms' that

structured gay men's relationships.<sup>1</sup> The manifest component of these rules refers to explicit agreements about for example, with whom sex is allowed, where it happens, what kinds of sex take place, where the other partner is, the number of times it can happen with the same person, and what is spoken about to the other partner. The functional components of relationship agreements refer to the purpose of having such rules in the first place. For example, rules can be about maintaining the primacy of the relationship, thereby differentiating it from other encounters, or simply to avoid irritation or confrontation between partners in a relationship.<sup>2</sup> The authors also refer to several other studies of gay relationships mostly undertaken prior to the HIV epidemic. These studies describe a number of different agreements, as well as changes in relationships over time. Many of these agreements were related to stress reduction, jealousy, fears, anger and conflict associated with sex

outside the relationship. Other research on relationships explored longevity, satisfaction, commitment, security, and frequency of sex.<sup>3</sup>

Qualitative research by Worth et al. investigated democracy and openness in gay men's relationships.<sup>4</sup> Although published in 2002, this article returns to some of the research concerns of the 1970s and 1980s, exploring the issues of monogamy, trust and negotiation. Although most men in the study prized monogamy they also recognised a certain inevitability of sex outside the relationship. Traditional notions of masculinity were also identified in this study, particularly as they related to the ability to discuss emotional needs. The authors caution against assuming that same-sex relationships constitute a radical transformation of intimacy or that they escape the values and norms of dominant heterosexual social institutions, such as those of romantic love and masculinity.

The exploratory nature of this research on gay men and relationships was lost somewhat as attention became concentrated on HIV transmission. Notable exceptions were Kath Weston's study of gay men and lesbians in the San Francisco Bay Area<sup>5</sup> and Judith Stacey's<sup>6,7,8,9</sup> research on gay male sexuality, intimacy and kinship in Los Angeles. Stacey provided an extensive analysis of the myriad forms of gay male kinship possibilities that included (but were not limited to) gay men with children. Of particular interest was the way that 'cruising' (the search for casual sex partners) and the ongoing relationships that sometimes developed out of these casual or commercial sexual encounters sometimes generated forms of kinship that crossed race, age, and class divisions.<sup>10</sup>

### Relationships agreements

Not surprisingly perhaps, the era of the HIV epidemic saw a definite narrowing of research on gay men's relationships to look at risk associated with HIV. This focus included HIV risk both within the relationship and from outside partners. Some researchers have sought to explain HIV risk within relationships through explanatory theories such as relationship investment<sup>11</sup>, romantic ideation<sup>12</sup> and intimacy<sup>13</sup>. What disappeared was qualitative research and with it the focus on the diversity of relationships, and the 'how' and 'why' elements of relationship agreements.

What became obvious was that sex without condoms was much more likely with relationship partners than with casual partners. Qualitative researchers in the UK found that unprotected sex was usually taking place in contexts where partners knew each other's serostatus, and made agreements about sex with other men, and so was a risk reduction strategy.<sup>14</sup> Quantitative research in Australia confirmed the existence of agreements between HIV-negative men in steady relationships not to use condoms and prevent HIV infection from other partners in the early 1990s and coined this 'negotiated safety'.<sup>15</sup>

Agreements such as negotiated safety assume a certain level of rational

decision-making and ability to communicate effectively. Also, the question of power remains unexplored, and as noted by Ridge much social research in the HIV era assumes equality in gay men's relationships.<sup>16</sup> Negotiated safety agreements also depend on at least two contingent elements: the certainty of knowing a partner's HIV status; and the feasibility of eliminating risks from outside the relationship.<sup>17</sup> However, in practice these agreements do not necessarily follow the recommended steps of establishing seroconcordance, discussing sex with other partners and coming to an arrangement about eliminating risk with other partners. For example, Davidovich, et al. found that 55% of men who had unprotected anal intercourse with their steady partners in The Netherlands did so outside negotiated safety guidance.<sup>18</sup> Similarly in the UK, Nearly half the men reporting unprotected sex with only with their main partner were unaware of their own HIV status, their partner's or both.<sup>19</sup>

In his US study Jason Mitchell found that only 58% of men concurred about explicitly discussing their agreement, 84% concurred about having the same type of agreement, and 54% had both men adhering to it.<sup>20</sup> In terms of negotiating and maintaining agreements, Prestage et al. found that a substantial proportion of men experience discomfort discussing sex and HIV with their regular partner.<sup>21</sup> This finding provides a challenge to

some important assumptions on which negotiated safety is based – clear and unambiguous agreements, and the ability to communicate breaches of the agreement to the other partner if and when they occur. However, the result is reminiscent of the earlier findings of Worth et al. who found that talking about non-monogamy was seen as threatening to the relationship, establishing trust was difficult, and making an agreement was not as step-wise, logical, equal or clear as presented in HIV education materials.<sup>22</sup> Prestage et al. found that a lower efficacy in communicating with their primary partner about sex and HIV status was a predictor of future likelihood of breaking agreements, and also predicted a decreased likelihood of informing a partner after a breach of an agreement.<sup>23</sup>

### Relationship ideals

The categorisation of relationships by gay men is not necessarily straightforward either. The term 'monogamish'<sup>24</sup> has been coined to describe couples who have threesomes, as it retains some elements of monogamy while also allowing the inclusion of outside sexual partners. One recent Australian study that examined relationships among young gay men found that although communication was identified as a relationship ideal, relationships were

*continued overleaf*

Of particular interest was the way that 'cruising' (the search for casual sex partners) and the ongoing relationships that sometimes developed out of these casual or commercial sexual encounters sometimes generated forms of kinship that crossed race, age, and class divisions.

often characterised by silence and the reluctance to acknowledge the possibility of sex with other partners.<sup>25</sup> This lack of clarification sometimes served to protect both sexual autonomy and the romantic ideal.

Even beyond young gay men it seems that being open about sex outside the relationships is not always easy or prioritised. For example, a study in the US of HIV serodiscordant male couples found that of those who had sex outside the relationship, only around one-third (36%) described their relationship as 'open'.<sup>26</sup> Another quarter (26%) reported that sex outside the relationship was suspected, and 26% reported that sex with other partners was kept secret or was unknown to the other partner.<sup>27</sup> (Data for the other couples was incomplete or discrepant.)

Mitchell et al. also examined the degree of concordance between male partners on their relationship agreement.<sup>28</sup> They found that men who adhered to their agreements were more likely to report being satisfied with their relationship and that they valued their agreement, as well as believing that their partner was more predictable and trustworthy. Men who concurred that a relationship agreement was in place were more likely to be satisfied with their relationship. However, consensus between partners on the type of sexual agreement they actually had was not related to any relationship variable, or to unprotected sex or HIV testing.

### **The meaning of agreements**

Hoff et al. examined relationship characteristics and motivations behind agreements among gay male couples with a particular focus on differences by agreement type and the concordance of partners' serostatus.<sup>29</sup> Honesty, trust, and a sense of protecting the relationship were cited as the most important reasons for agreements.<sup>30</sup> Protecting from HIV or STIs did not rate highly among any of the three groups in the study – open, monogamous or discrepant. (Only 8% of couples were in the latter category.) When analysed by serostatus of both

partners, only concordant negative couples listed HIV and STI prevention among their top motivators for making an agreement.

In this study there was no difference in relationship satisfaction between couples with monogamous and open agreements.<sup>31</sup> However, couples with monogamous agreements had higher scores on other relationship characteristics, such as investment in the sexual agreement, intimacy, commitment, attachment and equality. This finding of the similarity between couples with open and monogamous agreements echoes that of Wagner et al.'s study of male serodiscordant relationships in which they discovered that monogamous and 'open' couples were more likely to have greater consensus on relationship issues, as well as greater affection, and sexual satisfaction, than 'partial knowledge' or 'secretive' couples.<sup>32</sup> This finding suggests that having an unambiguous agreement about sex outside the relationship, regardless of the nature of the agreement, is associated with greater relationship quality in general, than not having an explicit agreement.

Drawing on equity theory, a recent study of Australian gay men in relationships with open agreements showed that men who perceived discrepancies in benefits between partners from the agreement – particularly those representing 'under-benefit' – were less satisfied with their agreement than were men perceiving equal benefit.<sup>33,34</sup> The kinds of benefits that were included in the analysis were how often they think their relationship partner has casual sex compared with how often they do themselves, and how attractive they thought their relationship partner's casual partners were compared with their own.

### **Recognition of relationships**

There has also been research interest in the recognition, or otherwise, of same-sex relationships. Judith Butler, however, proposed that the legitimisation of same-sex relationship by the state comes at the expense of relationships that fall outside these couple-centred relationship

forms.<sup>35</sup> These other relationships subsequently remain unrecognised and illegitimate. Examples are 'those who live non-monogamously, those who live alone, those who are in whatever arrangements they are in that are not in the marriage form' (pp.115–116). What Butler proposes is a resistance both to reducing kinship to the 'family' and to marriage defining 'the parameters within which sexual life is thought'.

The burgeoning literature on gay men and parenthood has some strong links with the way relationships are increasingly conceived and idealised. In Rabun and Oswald's (2009) study of young gay men in the United States, all of the participants indicated a desire and an intention to be a parent; and these men imagined parenthood only in the context of a relationship.<sup>36</sup> Parenthood may also be tied up with particular relationship ideals that may make it difficult for men to negotiate, or disclose, sex with other partners. An interesting US study among gay male couples with children found that agreements regarding sex with outside partners closely resembled those documented in studies of gay couples who were not parents.<sup>37</sup> However, men reported that parenthood typically decreased their opportunities to engage in sex with outside partners and also posed barriers to discussing these behaviours with their partners and health-care providers.

### **Conclusion**

This brief overview of research on gay men's relationships does not pretend to provide a comprehensive summary of the huge body of work on the area. Rather, it is intended to highlight some of the trends in this research over the last few decades. Unsurprisingly, HIV became a dominant concern during this period and questions of HIV risk have dominated the agenda. The findings from this research identified innovative strategies to minimise risk of HIV from regular and casual partners. However, since being promoted by health promotion agencies, research has shown that these strategies are not always implemented as intended. A common theme across several of the studies included here is that communication is

not always easy between partners, and that men do not always have a common understanding with their partner of the parameters of their agreement. A small number of studies have investigated relationship ideals and aspirations, which may also be changing over time. There is greater need for further work on gay male kinship more broadly including forms that involve more than two people, and also perhaps on the sexual relationship possibilities that are enabled by new technologies that provide the opportunity for a blurring of the division between regular and casual partners.

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## Having a brother with HIV: a family perspective, written by the oldest sister

By **Marilyn Edwards**

Dear brother,

You are the only boy in our family, the youngest of four and very much loved. Growing up with three strong sisters, you may not always have felt the love, but I trust that it definitely shows, now that we are all adults.

You chose a difficult path early on in life. I remember trying to persuade you as a teenage boy that our parents didn't really need to know that you were gay. This was thirty years ago – times were different and this was not a situation that our family had struck before. You were adamant, and so right. As a family, we would have been much less of a close unit without the challenge that you gave us to accept that the huge variety in the world applied also to us.

Mum, in particular, became your strong supporter in whatever you took on, becoming more involved that your sisters ever knew with gay groups and activities, and establishing close relationships with your friends. You worked in various roles, but it seemed that nothing gave you quite the satisfaction that you needed. So you left for Australia and found a community of caring, supportive friends, and established yourself in social work and serious study.

As it is now, in those days it was always exciting to have you come home. It was a special event, and we crowded in on you, eager to be with you and enjoy your company and have you back as part of our family, keen to introduce you to your new nephews and nieces.

One return home was for a different reason. We knew that you had cared for two friends with HIV, and that you were very involved in HIV/AIDS education. You came home to tell us that you had been diagnosed HIV-positive. This was about fifteen years ago, and you wanted to tell us and our parents. Another difficult task. Dad was not one to say much, and was true to form at that time. Over the years he and I would talk occasionally, Dad wondering how you really were ... Mum took it as the practical and loving mother that she was, committing herself anew to loving and caring for you, visiting often and sending socks.

From the beginning, we knew that there was serious medication involved, and that your health needed to be your top priority. Every time you come home, do you notice the careful attention we give to your physique? The inquiries designed to seem casual – have you had time for rowing, or the gym? Like my sisters, I have

photos of you in my head from recent visits, and each time I compare the latest with the previous pictures, and carefully analyse the comments about work and general busyness. There is an undercurrent of concern that we all feel, but are reluctant to address too blatantly, in case it is not what you want, and because we are a pragmatic lot. I do know that jokes between us now and then about the quantity of pills for daily consumption are precious to me, a sharing of your life, letting me see just a little of how it must be for you. And to hear from you when tests are imminent, or just past, is to feel a closeness that must be what family is supposed to mean.

While not with us all the time, you are a part of all of us. There is a bittersweetness to our hugs when you go home, not too far away, but still too far to be part of our everyday lives. As older sisters, ideally we would have you still where we can keep an eye on you, but that is not the way it is. So we look forward to visits, we wonder how you are, we email, and we trust that you know how supremely important you are to us.

Take care of yourself till next time,  
Your biggest sister.



## Not so alone: the importance of relationships in growing up with HIV

By **Angela Miller, Asha Persson** and **Christy Newman**

While there are over 3.3 million children under the age of 15 estimated to be living with HIV worldwide<sup>1</sup>, there are only around 80 children living with HIV in Australia<sup>2</sup>. While most people would rightly see this comparatively low figure as a great success, it also creates particular challenges for the young people themselves, who are scattered throughout Australia. In a country of over seven-and-a-half million square kilometres<sup>3</sup>, growing up with HIV can signal difference, aloneness and social isolation. Many young people

have been able to overcome these obstacles through the support and benefit of relationships, both personal and professional, to assist them in the management of living with HIV and enhancing their overall capacity.

This article provides a brief reflection about some of these familial, peer and health care provider relationships. It primarily draws on Angela's personal experience of working with this population, but also on findings from the authors' collaboration on a recent study of young people growing up with

HIV in Australia, which was conducted by the Centre for Social Research in Health (UNSW) in partnership with the Paediatric HIV Service at the Sydney Children's Hospital.<sup>4</sup> As a social worker at the paediatric HIV service from 2003–2013, Angela observed with interest how relationships of all types play an important role in the lives of these young people.

*continued overleaf*

Despite significant medical advances, the multi-generational factors in paediatric HIV remain unique: many young people with HIV have lost one or both parents to the disease and some have lost a sibling. Whilst the understanding and support from family members who are also HIV-positive can be incredibly helpful, some young people also experience challenges with these dynamics. Young people may have taken on the early experience of their parent's diagnosis, directly impacting their own thoughts on disclosure, stigma and shame. Some have witnessed the ill health of family members, and subsequently worry about their own future. Despite the desire to disclose their HIV to a friend, some feel pressure not to, as this may automatically lead to the unwanted disclosure of their mother's HIV.

For some, the need for privacy will impact on all aspects of their life. Having attended the funeral of one young person, Angela recalls an open discussion with several of the young person's HIV-positive friends following the wake. Other than immediate family, Angela and the few friends from camp had been the only people at the funeral aware of the young person's HIV status. Others were aware only of the

secondary condition which had led to her death. As her school friends read a lovely eulogy and spoke of the strength of their friendship, the young people living with HIV sat anonymously, quietly dealing with their own grief.

Afterwards, they spoke about whether this too would be their future. They also pondered, as one young person put it, 'how these people can speak about their close relationship when they don't even know about the biggest thing that affected her?' All too aware of the impact of the HIV diagnosis on their friend's family, the group supported each other through this difficult time and pondered whether there will come a time when they themselves might feel comfortable to be public about their health. Poignantly, the loss of their friend and the added difficulty of the funeral allowed the group to strengthen their bond with each other.

So, is HIV enough of a commonality in young people to create a bond regardless of other factors? International research suggests that young people with HIV feel that they can manage better if they have friends who share their condition.<sup>5</sup> As our own recent research study reveals, many of the young people attending the yearly Camp Goodtime and the Positive Kids

Camps would agree with this finding. Knowing other HIV-positive peers helps young people to deal with the associated challenges they face: feeling different, keeping the secret, managing medications, preparing for relationships and disclosure, managing loss and more. Interestingly, in our interviews with young people in Australia living with HIV, as well as with clinicians working with this population, a consistent theme across both groups was the desire of the young people to be and feel 'the same as everybody else', juxtaposed by opposing feelings, such as feeling the burden of secrecy, fear of disclosure and feeling different.<sup>6</sup>

So, as a group of young people gathers on the grass at camp after a day of getting to know one another, some will sit with their backs to each other, some will need to bounce a ball or play with a stick or scribble on paper, some will need to look disinterested and bored, almost waiting for the 'others' to give permission to be interested. Others will sit tensely, watching for cues about what to do. If the facilitator is able to respond to this group dynamic by gradually introducing ideas to externalise and normalise some of the thoughts leading to these emotional reactions, and then ask for input from the group, group support naturally follows.

On many occasions when this technique has worked, the change in the demeanour and visible relief on the faces of new participants has been remarkable. As one young person commented about the Positive Kids Camp: 'I have somewhere I belong ... and it's a wonderful feeling' – (World AIDS Day interview, 2006).<sup>7</sup>

And in one of the interviews conducted for our study, a young person said of camp:

*Oh, such an important, such a pivotal point in my, my life having people around you that understand and being able to cry, and remember people in the past, and be able to talk about medicine and side effects without having to explain. It was the one time*

As our own recent research study reveals, many of the young people attending the yearly Camp Goodtime and the Positive Kids Camps would agree with this finding. Knowing other HIV-positive peers helps young people to deal with the associated challenges they face: feeling different, keeping the secret, managing medications, preparing for relationships and disclosure, managing loss and more.

*of the year where you felt normal,  
where you felt like part of something.*

After camp, participants return to their homes throughout Australia and New Zealand, hopefully with the knowledge that they are indeed not as alone or different as they had previously thought. Whereas previously these peer relationships were only able to be developed through biannual face-to-face visits, young people can now achieve ongoing connection and support via social media, which for some has had a great impact on their experience of social isolation and 'aloneness'.

The strength of relationships with their health care providers may also impact on young people's ability to manage their HIV. Frequent in-depth contact with a paediatric service from an early age, will allow many young people to develop strong links and trusting relationships with their health care professionals. While this can be very helpful in sustaining engagement, it can also create dependency and a sense of responsibility (both positive and negative) for both parties.

Paradoxically, whilst health care transition from paediatric to adult services aims to be a smooth process which is completed over time, its peak comes at an age when so many other factors are impacting on young people. As life becomes overwhelming, HIV may slide down the priority list for many young people and, as a result, both medication adherence and engagement with health services may be affected. Young people may be more likely than ever to disengage from services at the time when they may need them the most. Adult service providers may therefore be starting the relationship from a difficult position – aiming to develop a supportive and trusting relationship with the young person in these challenging circumstances.

Our interviews with clinicians here in Australia made note of these challenges and the need to provide care beyond the 'usual clinical interactions'.<sup>8</sup> It is reassuring to note that in what can

be a potentially rigid medical model, focus can be placed on the development of clinician/patient relationships to ensure that successful, ongoing and individualised care is achieved.

This brief reflection by no means intends to simplify the nature of relationships in growing up with HIV, which no doubt have many layers and complexities. Rather, it intends to provide some fuel for thought about the importance of not underestimating the power of relationships of all kinds for young people living with HIV. We hope that our forthcoming articles reporting on the views of young people themselves will contribute to our understanding and appreciation of their experiences, including the important role of relationships.

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Whereas previously these peer relationships were only able to be developed through biannual face-to-face visits, young people can now achieve ongoing connection and support via social media, which for some has had a great impact on their experience of social isolation and 'aloneness'.



## HIV and relationships: facing a new reality

By **James May**

James May speaks with three HIV-positive people in rural NSW. They share very different stories about their relationships with sexual partners, family and the HIV community.

### **Mark\***

Mark is a 51 year old Aboriginal man who lives in rural NSW. He's been HIV-positive since 2007 and says that the diagnosis rocked his world. 'I thought I was cactus until I realised that a HIV diagnosis doesn't mean you'll die of AIDS.' He says it's taken a few years to come to terms with being HIV-positive but that it's made him take ownership of his health. Mark has given up smoking, drinking and drugs and is managing better than ever. 'I don't wanna be influenced by mind altering substances,' he says. 'I wanna live in my body and experience life.' Mark is also diabetic and suffered a heart attack in 2005. He underwent

open-heart surgery and says that these health challenges also helped him cope with the HIV diagnosis.

Mark doesn't like to disclose his HIV status to many people, not even dear friends. 'It's a need to know basis except with sex partners,' he says. He is starting to surround himself with people he can be open with and steering clear of those he can't. 'I don't wanna be on the receiving end of people's insecurities. I'm already on the receiving end of it because I'm Aboriginal.' Mark says he is still dealing with abandonment issues from childhood and finds it hard to deal with people judging or rejecting him. 'I'm still coming to terms with the diagnosis and the ramifications of it. Maybe I'm still a bit ashamed. It makes me feel bad about myself sometimes.'

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\* Not his real name.

Mark tried a relationship with an HIV-negative guy but says it was very short-lived. He prefers to get involved with other HIV-positive guys because it feels like they're on equal ground. 'The minute I disclose my HIV status to a negative partner I don't see them for dust. I have some poz mates with an amazing sex life because they're more comfortable with being poz. I still feel like I'm walking through a minefield.'

Mark doesn't speak to the Indigenous community about his HIV status. 'Being gay is not accepted,' he says. 'Being HIV-poz would blow their minds. You could have cancer or heart disease and that's just part of the hard luck story of being a black fella, but being HIV-poz means you're scum, lowlife.' Mark doesn't have much contact with his birth family either. 'They couldn't cope with my sexuality, let alone HIV. I came out a long time ago and they still haven't come to terms with it. I have more of a spiritual and gay family now.'

Mark has always known about ACON and other HIV services. He doesn't necessarily feel like he has much in common with people who use those services but he has gravitated towards more HIV-positive people since his diagnosis. 'HIV services were useful, especially in the first few years. They put me in the loop and showed me how to access things. Now I'm on meds and my GP is sorted I don't need so much contact.' Mark explains that he wouldn't feel comfortable disclosing his HIV status to Aboriginal health organisations. 'It could be socially damaging to disclose to an Aboriginal health body,' he says. 'I don't trust where the information would end up.'

Mark says he's been on a health, nutrition and emotional journey since his heart attack and that HIV has inspired him to stay on track too. He is also a visual artist and this is something he loves dearly. 'It's a meditation and does powerful things for me. I will always paint. I do it for the emotional and spiritual place that it takes me and no drug will get me there.'

## Darren

Darren lives in Northern NSW and was diagnosed HIV-positive 14 years ago, at the age of 20. He was travelling through India at the time when he suffered a debilitating seroconversion illness. Darren says the diagnosis was a big shock because he was so young and didn't know much about HIV. 'I had only come out in the previous few years and was still learning about safe sex and HIV. I only knew about it from people dying in the '80s and '90s.' Darren was overwhelmed with shame, yet felt a sense of anger and injustice at contracting the virus so young. 'I couldn't believe it happened to me. I thought it was something that affected older generations.'

According to Darren, his relationship with family benefited in the long run as a result of the diagnosis. 'It was rocky for a while but flowed much better when they offered their unconditional support. They had had huge expectations of me but they accepted that HIV meant we all had to face a new reality.' Darren says that living with HIV has made him a more authentic person, especially with family. 'HIV has motivated me in terms of life purpose, emotional development and spirituality. Everyone in the family has evolved more because of HIV.'

Darren says that his self-esteem suffered after the diagnosis even though he didn't look any different. 'I was in the prime of my sexual life but I didn't have the confidence I might've otherwise had. I often felt unattractive and didn't seek out many sexual

partners.' He says that HIV created insecurity around sex and relationships and he gravitated towards people who weren't necessarily ideal. 'I got involved with people who didn't value me as much as was healthy for me.'

Darren says that he's now had more sexual partners who are HIV-negative than positive and hasn't faced much rejection over his HIV status. However, he has experienced the underlying fear around HIV transmission that can arise in a serodiscordant relationship. 'I've felt more sexually inhibited due to the fear of passing the virus on than I was about catching the virus.' Darren is now in a relationship with a HIV-positive man and says there's a mutual understanding of the way HIV impacts both of them physically, emotionally and spiritually. He says it can be difficult for them to care for each other when their health is challenged at the same time though.

Darren didn't really engage with the HIV sector till several years down the track when he got involved in peer support groups in Melbourne. He went on to work as a facilitator and says this was an empowering process. 'I grew quite a bit and really came to terms with HIV.' Darren then went onto being a Positive Speaker with Living Positive Victoria and says he enjoyed educating people in the broader community, particularly in schools. 'I met people who had been living with

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Mark ... prefers to get involved with other HIV-positive guys because it feels like they're on equal ground. 'The minute I disclose my HIV status to a negative partner I don't see them for dust. I have some poz mates with an amazing sex life because they're more comfortable with being poz. I still feel like I'm walking through a minefield.'

HIV for a long time. It was the best peer support I could ever get.’

Darren is currently a volunteer counsellor with ACON Northern Rivers and says he might like to continue speaking in the medical system and aged care services. ‘Many of us are getting older and may need care in future so we need to raise awareness. There’s still a long way to go in terms of HIV stigma and I can always have a broader reaching voice. I feel confident and empowered with HIV. I honestly don’t care who knows my status anymore.’

### **Kate**

Kate lives in rural NSW and was diagnosed HIV-positive in 1990. She had been in a relationship with a positive man for seven years at the time. ‘It was a terrible shock. I recall an incredible grief that I’d never have children.’ Kate’s partner was always healthy and she says they thought he wouldn’t succumb to the virus. ‘My partner never had regular T-cell check-ups because he seemed so well.’ Kate says the physicians they saw at the time of her diagnosis were informative but it was early days. ‘They had a lot of fear which was understandable but it turned us off engaging with them. We thought they were being hysterical. Looking back, we were ignorant,’ Kate says. ‘We were very well, but didn’t know the effects of the virus might not show up till years later.’ Kate’s partner died in 1994. She says his death made her live life more fully. ‘The more aware we are of the impermanence of life the more alive we can be.’

Kate says that when she first tells a man she’s HIV-positive they usually say they’ve never known someone with HIV. ‘They’re straight – it’s a different world. Some have been open to me educating them and trust me completely. Some have more doubts.’ Kate insisted on using condoms but says that the men wanted to dispense with them down the track. ‘I was insistent because I’d hate to pass the virus on,’ she says. Kate is glad that

it’s less of an issue these days with the efficacy of medications and the fact that many HIV-positive people are treatment compliant and have undetectable viral loads.

Kate didn’t tell her family about her HIV status until her partner became very unwell. She says they were always supportive though and it’s become a non-issue as they’ve grown older and faced their own health problems. ‘I grew up in a theatrical family. They were used to gay men and always open-minded.’

Kate believes that HIV service providers do the best they can with the resources they have and that they’re very committed people. The men she encounters in the HIV community are very accepting of her, but she says that HIV-positive women are harder to reach. ‘I’d like to see more women at social outings and treatment events. Some women are just getting on with their lives but there’s a high percentage who have a lot of fear around being known as positive. I’m concerned they may be missing out on emotional and financial support if needed, and being kept informed about medical advances.’

Kate says that HIV has given her more insight about her own health issues and the health of society in general. She has always been conscious of good nutrition and alternative medicine. ‘Managing HIV has made me more appreciative of allopathic medicine too.’ She now uses a combination of both and invests heavily in vitamins and supplements which are vital, she says.

Kate feels pretty good with HIV these days. ‘I’m glad that we have good access to HAART (highly active antiretroviral therapy). We’re better off than most people in the world in that sense. But I am aware of the side effects on my body which aren’t always comfortable. Also, I’m concerned that with the new government, people in need may be less able to access support.’

HIV has never undermined Kate’s self-esteem but she is more conscious when she meets a new person in the medical

arena. ‘In my experience, some clinical staff who have little experience of HIV have tended to be insensitive – more so than people in general. Prejudice can have a stronger impact when it’s not spoken. I can’t deal with people’s fear if we can’t talk it out. If we can’t talk it out it’s their problem.’

### **Summary**

Everyone’s experience of living with HIV is unique. The way a person reacts to a positive diagnosis, how they come to terms with HIV and their relationships with significant others is varied. The diagnosis was a difficult time for the participants interviewed for this article. Yet they took control of their health and thrived while living with HIV. Some had felt that their self-esteem was undermined but are overcoming this. Healthy, supportive relationships with friends and family are very beneficial, as are strong relationships with other HIV-positive people.

These participants have faced their fears around negotiating safe sex and disclosure – and some have had very encouraging experiences with HIV-negative partners. It’s likely that on-going public education and the efficacy of medication is contributing to this, as well as people’s own determination to be open and honest. There is no doubt that living with HIV still presents many challenges. However, these people have shown that a HIV diagnosis can produce a better quality of life and stronger, healthier relationships.

**James May is a freelance writer from NSW who regularly contributes to the HIV sector. His articles have appeared in *HIV Australia* and *Positive Living*.**



## HIV treatment and transmission in gay male serodiscordant relationships: the Opposites Attract Study

By **Benjamin Bavinton**



### OPPOSITES ATTRACT

THE STUDY OF RELATIONSHIPS BETWEEN  
HIV POSITIVE AND NEGATIVE GAY MEN

HIV serodiscordant couples – where one partner is HIV-positive and the other is HIV-negative – are a key context of HIV transmission risk in both heterosexual and gay male populations. Amongst gay men in Australia, for example, it has been estimated that up to nearly 30% of new HIV infections occur in the context of relationships.<sup>1</sup> While condom use typically tends to be higher in gay male serodiscordant couples than in seroconcordant couples<sup>2</sup>, it is clear that many gay male serodiscordant couples choose not to use condoms with each other, perhaps using other risk reduction strategies to prevent transmission.

One potential strategy is the use of antiretroviral treatments to prevent

transmission. This strategy of reducing HIV transmission risk by placing the HIV-positive partner on antiretroviral therapy (ART) irrespective of stage of HIV infection has become widely known as ‘treatment as prevention’.<sup>3,4,5</sup>

Studies in heterosexual HIV serodiscordant couples have provided critical evidence on the role of HIV treatments and undetectable viral load in reducing the risk of HIV transmission. A number of observational studies, primarily in African heterosexual serodiscordant couples, have demonstrated a link between HIV treatment, undetectable

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viral load and reduced transmission risk.<sup>6</sup> In 2011, the early results of a randomised clinical trial, HPTN 052, provided conclusive evidence that when the HIV-positive partner is on ART, transmission risk is dramatically reduced by 96% in heterosexual serodiscordant couples.<sup>7</sup>

We now know that ‘treatment as prevention’ is an effective means of reducing HIV risk for heterosexual serodiscordant couples. However, to date, there is no conclusive evidence on the relationship between ART and transmission in gay male serodiscordant couples.<sup>8</sup> HPTN 052 did include 37 gay male couples, however there were no linked HIV transmissions within these couples and this number was too small to provide any meaningful evidence on HIV treatment and transmission risk in gay men.

Given that the risk of HIV transmission via anal intercourse is about 10 times greater than for vaginal intercourse<sup>9</sup>, it cannot be assumed that the effectiveness of ‘treatment as prevention’ will be identical for the two types of sex. As anal intercourse is not uncommon among heterosexuals (for example, 20.9% of adult heterosexual men and 15.1% of adult heterosexual women in Australia report anal sex in their lifetime<sup>10</sup>), findings among gay men may also have broader relevance for the effectiveness of ‘treatment as prevention’ in heterosexuals.

While most scientists believe ‘treatment as prevention’ will result in a reduction in risk in gay men, it is not yet clear by how much. Due to the size of the transmission risk reduction found in HPTN 052, it is likely there will never be another randomised clinical trial of ‘treatment as prevention’, as it would be unethical to place couples into a ‘no treatment’ arm in light of the immense protective effect of treatment. This means that there is an important role to play by observational studies of HIV treatment and transmission to determine the effectiveness of ‘treatment as prevention’ in gay men.

Globally, there are currently two ongoing studies designed to explore the

'treatment as prevention' hypothesis in gay male serodiscordant couples.

First, the Opposites Attract Study is to our knowledge the only research study in the world exclusively examining the association between HIV treatment and HIV transmission within gay male serodiscordant couples. It is a prospective longitudinal cohort study of such couples, running from early 2012 until the end of 2015. While originally envisioned to be conducted in 14 Australian clinical sites in Sydney, Melbourne, Brisbane and Cairns, the study will be soon be expanding internationally to new sites in Brazil and Thailand.

The couples attend a participating clinic at least twice per year for blood tests and STI tests, and complete a detailed questionnaire after each clinic visit. In cases of seroconversion in the initially HIV-negative partner, phylogenetic analysis will be used to determine whether the transmission was within the couple, or whether it was from an outside partner. Additionally, for couples participating in Sydney, Bangkok and Rio de Janeiro, HIV-positive partners can also elect to join a sub-study looking at HIV viral load in semen.

Couples are eligible to participate if one partner is HIV-positive, the other partner HIV-negative, they have regular anal sex with each other, and still expect to be having sex with each other in three to six months' time. Previous research has demonstrated that HIV transmission is more likely in the early stages of relationships.<sup>11</sup> Consequently, the eligibility criteria were designed to ensure that couples in very new relationships – and indeed, sexual partners who do not consider themselves to be in relationships at all – are welcome to participate. HIV-positive partners in the couples can be currently taking ART, not taking ART, or can start taking it at any point during the study. Furthermore, the study is open to couples who always, sometimes or never use condoms when having anal sex with each other.

The second study of 'treatment as prevention' internationally is

PARTNER ('Partners of people on ART – a New Evaluation of the Risks'), which is being conducted in 72 clinics across the UK and Europe.<sup>12</sup> PARTNER is open to both heterosexual and gay male serodiscordant couples and explores the absolute level of HIV transmission risk in serodiscordant couples where the HIV-positive partner is on ART and has undetectable viral load, in the absence of condom use. It is also an observational cohort study where couples are followed up over time, and will also utilise phylogenetic analysis to determine if HIV transmissions are from within the couple or from outside partners.

The PARTNER Study focuses on measuring the HIV incidence in both heterosexual and homosexual serodiscordant couples having unprotected anal and/or vaginal intercourse, and is restricted to couples where the HIV-positive partner is receiving ART and has undetectable viral load at enrolment. By contrast, Opposites Attract will allow the calculation of HIV incidence in couples where HIV-positive partners are on ART or not on ART, and with undetectable versus detectable viral load (and semen viral load in a subsample of couples). Furthermore, the detailed behavioural and attitudinal data from the participant questionnaires will allow exploration of many contextual factors associated with HIV risk, behavioural risk compensation, and the negotiation of sexual practice within couples.

As governments and communities world-wide move forward with HIV prevention strategies incorporating 'treatment as prevention', it is critical that studies on HIV treatment and transmission specifically within gay male serodiscordant couples form part of the evidence-base guiding the response.

*Opposites Attract is recruiting now. For more information on the Opposites Attract Study, please visit [www.OppositesAttract.net.au](http://www.OppositesAttract.net.au)*

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## A matter of trust: navigating HIV disclosure and the law within relationships

By **Amanda Jones** and **Indraveer Chatterjee**

Disclosure of one's HIV-positive status can often be a difficult issue, particularly in the context of relationships. Stigma militates against it, and the early stages of a relationship can be complicated enough without dealing with the misunderstandings that an HIV-negative partner may have around HIV. However, normalising HIV within the broader community cannot happen without people with HIV being able to speak about their status openly and confidently. The law has some utility here, in the slow creation of behaviour change, and through the provision of an effective mechanism to prevent breaches of privacy.

In most cases individuals entering a new relationship will want to

disclose their status regardless of the law. Disclosure can be beneficial in that it can serve as a way of accessing support. However, it carries practical and legal implications – the increased trust and wellbeing that comes from the sharing of personal information is counterbalanced by the risk of rejection, and the vulnerability that a person with HIV may face from the abuse of that information.

Public health laws throughout Australia – sometimes openly, and sometimes by inference – encourage people with HIV to disclose at the inception of sexual relationships, despite there being little public health utility in such a position. Paradoxically, having impelled disclosure, the law does little to then

protect that information. The truth is that in private relationships, trust is the only effective protection in the abuse of confidential information.

### **Public health laws and disclosure of HIV**

Most states and territories have public health laws relevant to people with HIV. Individuals with HIV, in the conduct of sexual relationships, are often either explicitly required or implicitly urged to disclose their status prior to sexual intercourse. For instance, Tasmania requires a positive person to disclose their status to any *sexual contact*<sup>1</sup>; NSW requires disclosure prior to *sexual intercourse* **but** it is a full defence to the charge if *reasonable*

precautions are taken<sup>2</sup>; and Victoria does not require disclosure.

Disclosure laws vary from state to state, and HALC has produced guides to disclosure for NSW, South Australia and Western Australia which can be referred to for additional information. The laws are not necessarily straightforward. For instance, in NSW the relevant section that governs disclosure is s79 of the *Public Health Act*.

The NSW Act requires a person with HIV to disclose their HIV status to a new sexual partner unless they use reasonable precautions to prevent transmission. Reasonable precautions usually refer to use of a condom and lubricant, although this has yet to be determined by the Courts<sup>3</sup>. Taking reasonable precautions will constitute a full defence in NSW. It should be noted however, that disclosure laws vary depending on the state or territory that an individual lives in. A person may be required to disclose their status under law and reasonable precautions may not be an adequate defence, depending on where they live.

As indicated above, while the law in NSW does not mandate disclosure of a person's HIV status, at the very least it strongly pushes a person to disclose their status to new sexual partners. The issue here then becomes that the law currently does not provide effective protection for individuals who do disclose their status.

## Potential issues upon disclosing

In order to demonstrate potential issues upon disclosing your HIV status to a partner, below are some case studies from our practice. While disclosure often results in acceptance and support, such acceptance and support may often be withdrawn upon the breakdown of the relationship. We also set out any possible legal remedies, if any.

### Dan and Bobby

Dan and Bobby have just entered a relationship with each other. Dan has not told his family of his HIV diagnosis as he is still coming to terms with it himself. Dan is HIV-positive,

whilst Bobby is not. Dan wants to be open and honest with him about his HIV status, so before having sex, Dan discloses his status to Bobby.

Bobby is initially taken aback but is happy that Dan told him that he was HIV-positive. Their relationship continues and Dan appreciates the emotional support from his partner.

Unfortunately, as the relationship continues Bobby starts becoming controlling and emotionally abusive. When Bobby is angry with Dan he will punish him by disclosing his HIV status to various friends, when he knows that Dan has not told them yet. Dan is becoming increasingly hurt by Bobby's disregard for his feelings and his personal health information. Since Bobby refuses to stop his behaviour, Dan eventually leaves him, which sends Bobby into a rage.

As punishment for Dan leaving him, Bobby instigates a campaign to embarrass Dan as much as possible. He starts by creating a fake Facebook account and sending all of Dan's Facebook contacts messages, disclosing Dan's HIV status. Bobby then emails all of Dan's family telling them the Dan is in a homosexual relationship and is HIV-positive. He then sends anonymous emails to Dan's place of employment telling them that they

should be careful since they work so closely with an HIV-positive man.

Dan is obviously devastated by this malicious behaviour and gross breach of his privacy, but what can he do?

## Legal remedies

Dan's situation is complex, due to many issues. In a new era where social media is commonplace, issues of international jurisdiction become apparent. Sadly the answer is that there is not much Dan can do. There are two pieces of legislation that deal with privacy issues, namely, the Commonwealth *Privacy Act 1988* (Cth) and in NSW, the *Health Records and Information Privacy Act 2002* (NSW). These Acts predominantly focus on the handling of personal information by governmental and/or healthcare agencies. The Commonwealth Act does not apply at all to the collection, holding, use, disclosure or transfer of personal information by an individual.<sup>4</sup>

The NSW Act can deal with complaints against private individuals<sup>5</sup>, however, there is an exemption for privacy complaints made in connection with personal, family or household affairs, in relation to an individual's health information<sup>6</sup>.

*continued overleaf*

Public health laws throughout Australia – sometimes openly, and sometimes by inference – encourage people with HIV to disclose at the inception of sexual relationships, despite there being little public health utility in such a position. Paradoxically, having impelled disclosure, the law does little to then protect that information.

Since Dan's breach of privacy is directly connected to his family or household affairs, Bobby would be exempt from a complaint being made against him. At any rate, the prospects of success for a privacy complaint are very poor.

Dan's only remedy would be to institute a civil claim against Bobby for breach of confidence, however these claims are slow and very costly and this area of law continues to be uncertain and is in an early stage of development. Its utility against an individual (as opposed to a media corporation) is debatable.

His last option may be to seek an Apprehended Violence Order (AVO) against Bobby that would prevent Bobby from a particular action, such as posting Dan's private information online. Obtaining admissible evidence of Bobby's actions would be difficult, necessitating collection of witness statements of the actions. Where anonymous accounts are used, demonstrating that the disclosure was caused by Bobby would be extremely hard. Courts are often reticent to be involved in 'private' disputes, particularly where there is no overt violence. Finally, such applications – if unsuccessful – can result in Dan being liable for Bobby's legal expenses. Even with an AVO, Bobby could easily use fake social media accounts to harass Dan. There is little to nothing that can be done to resolve Dan's privacy issues.

### Jeff and Rachel

Jeff and Rachel have been married for ten years and are now going through a bitter divorce. They have two children and are in the middle of court proceedings to determine whom the children will live with. Prior to getting married Rachel was diagnosed with HIV. Jeff was aware of her status throughout the entire duration of their marriage and was accepting of it. Now that they are getting divorced Jeff has decided to raise the issue of Rachel's HIV status during the proceedings, for a tactical advantage. What, if anything, can Rachel do?

### Legal remedies

Unfortunately for Rachel, there would not be any legal remedies available to her during the proceedings. Legal causes of action do not generally lie against individuals in relation to evidence they give in court.<sup>7</sup> The pressure of having her diagnosis discussed in court and being examined on it may well distress Rachel. It could result in other family members or friends who are called to give evidence during the proceedings learning of her diagnosis. At best, Rachel could request a suppression order at the end of the proceedings so that her HIV status is not referred to in any published materials but it would be extremely difficult to restrict its discussion during trial, even if its relevance is tenuous at best.

### Conclusion

The law thus provides little to no protection around privacy breaches in interpersonal relationships; once an individual's privacy is breached, there are few effective and practical remedies available. Many would argue that except where there is coercion to disclose HIV status, this is as it should be – that the law has no place in regulating issues faced by people with HIV in their personal lives. This ignores the fact that, at present, the law does intrude into the personal affairs of individuals, but only to the detriment of people with HIV.

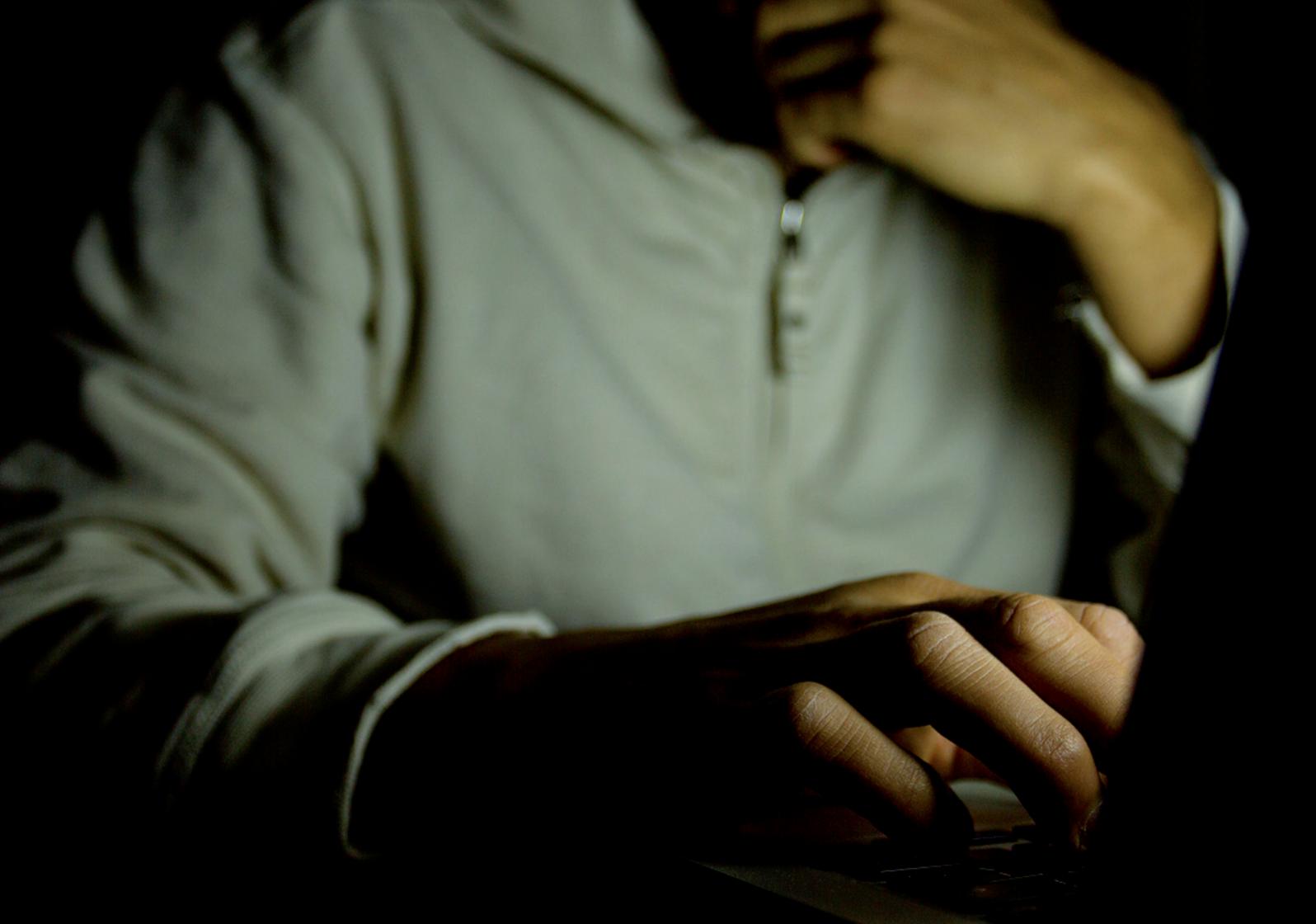
We believe that there should be legal remedies for the likes of Dan and Rachel. The law should provide appropriate privacy protections for HIV-positive people so they may conduct their personal relationships secure in the knowledge that they have legal recourse should their status ever be used against them. This can only assist in reducing discrimination and stigmatisation of people with HIV on a societal level.

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- 7 For instance, defamation claims cannot be taken; see s27 *Defamation Act 2005* (NSW).

The law should provide appropriate privacy protections for HIV-positive people so they may conduct their personal relationships secure in the knowledge that they have legal recourse should their status ever be used against them.

**Amanda Jones and Indraveer Chatterjee are solicitors at the HIV AIDS Legal Centre (HALC). They have an interest in the role of the law in the realisation of human rights. The opinions expressed in this article are those of the authors, not necessarily reflecting the views of HALC.**



## Awkward interactions: disclosing HIV online

By **Abigail Groves**

When I was studying internet use ten years ago, one question that exercised HIV researchers was whether the emergence of the internet would increase HIV infections. This was at a time when HIV diagnoses among gay men were beginning to increase again, after declining consistently for a decade.

HIV researchers focused on the association between internet use and risky sexual behaviours. As Grov et al. note, gay men who use the internet to find sexual partners tend to have sex more often and with more people, though the precise nature of this 'association' was often a bit unclear.<sup>1</sup> One of the things that I found frustrating was a tendency among researchers to conflate the internet with the people who used it, as if logging onto the net would somehow, in itself, give you a sexually transmissible infection (STI).

This tendency was not confined to HIV. At that time, writing about the internet was full of such scare-mongering. Historian Robert Reynolds has characterised such thinking as different versions of 'the web made me do it'.<sup>2</sup>

Ten years later, internet use has become so widespread and normalised that questions like these seem irrelevant. What is true is that the internet has made it easier for many of us to find someone to have sex with. Earlier media technologies such as telephones and newspapers did this too, but the internet has made it a lot easier. This is, I suggest, particularly true for gay men.

In 2008, Reynolds described a visit to Gaydar, then 'the most popular gay Internet site', and trawling through hundreds of profiles. He likened it to

a new kind of sexual consumerism, 'shopping for cock'.<sup>3</sup> The internet has, as Reynolds acknowledged, provided an explosion of sexual possibilities for gay men. Good sex, bad sex, casual sex, kinky sex, group sex, safe sex, hot sex – all kinds of sex.

But where is HIV in this sexual market place? Where five years ago Gaydar was the most popular gay site, it is now one among many. One man that I spoke to for this article called it 'a legacy site – mostly for old school gay men'. The internet has moved at breakneck speed. Smart phones and mobile apps now provide mobile access to the internet, and the popularity of apps like Grindr and Scruff testifies to the usefulness of these technologies.

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Along with the proliferation of opportunities for sex, the internet has produced a proliferation of opportunities to negotiate sex. HIV and STIs are in these negotiations. 'The street finds its own uses for things,' wrote science fiction author William Gibson. Now every tick box, every word on a profile, every message answered – or not answered – is part of that negotiation. Each is full of possibility – and risk – in almost equal measure.

'Most negative men don't disclose a status online,' says James, an HIV-negative man that I talked to for this article. 'Some will have a standard thing like "DDF" (drug and disease free) on their profile. Sometimes they say, "DDF since a particular date," to say they have tested recently.'

James believes that most HIV-positive men do not disclose their status online. 'My experience is that most positive guys will avoid disclosing wherever they can.' James pointed to the subtleties of disclosure online. 'There are some guys who will say they are positive on their profile but don't include a picture of their face. If someone contacts them,

they can choose when or whether to out themselves.'

'There are positive guys who write in their profile that they are positive. They make a big deal of it so that people notice it and include a face pic as well, so they are effectively outing themselves to everyone.' James surmised that these were mostly older gay men who have been positive for a long time, who disclose in order to forestall rejection by others. This fear is well-founded: the HIV-negative men in one study (Groves et al., 2013) stated that although they routinely used condoms, they would avoid having sex with men they knew to be positive.<sup>4</sup> Studies of positive men have found that most have experienced such rejection at some time.<sup>5</sup>

Fear of sexual rejection is usually cited as the prime reason for avoiding disclosure, but the stigma surrounding HIV has many other effects, well beyond sex. Indeed, one of the opportunities that the internet has provided is the ability to rapidly disseminate information – even when that information is private or inaccurate and its dissemination may be deeply damaging. 'I have seen some appalling behaviour online,' says James. 'Guys being outed all over the place. Trash talk directed at poz guys. It

happens quite a bit. Most guys won't disclose until they're confident they are talking to someone who is sane and sensible.'

This does not sound like a very safe or supportive environment for men with HIV. 'Instead of trying to negotiate disclosure on those mainstream sites, they just left. They have gone to other sites like BBRT [BareBack Real Time].' The proliferation of different sites and apps in the last five years means that different sites cater to different sub-groups, as users vote with their clicks.

This was confirmed by positive men that I spoke to. 'I would avoid Gaydar or Gay.com,' says Sam. 'They are twinkly. There's a lot of really young guys and newbies. All talk, no action.' Instead he says, 'I use Scruff. If I am looking for sex, I want someone who's up for it. I don't want to pussyfoot around.'

Even on Scruff, Sam says he prefers the discretion of being able to choose how and when he discloses. 'My profile says, "Ask me" about my HIV status,' he explains, 'And when they ask, I tell them I'm positive. My experience is that people whose profiles say "ask me" or "safe sex" usually turn out to be positive.'

Sam emphasised that the responsibility for initiating that conversation should not just fall on him as a person with HIV. 'I say I'm looking for raw sex, so negative guys need to take some responsibility and ask me,' he said. 'The last thing I want is a conversation about HIV status after I've just had sex. I have been in that situation ... some guy knew I was looking for bareback sex and he was too. He didn't say anything and he was so into it that I just assumed that he must be positive too. It turned out he wasn't and he got all worried. I packed him off to get [post-exposure prophylaxis (PEP)] and it was fine, but I could have done without it.'

Another positive man, Ben, says he does disclose his HIV status on his profile. 'I am positive and I don't like condoms,' says Ben. 'I'm looking for other positive guys. I don't want

Fear of sexual rejection is usually cited as the prime reason for avoiding disclosure, but the stigma surrounding HIV has many other effects, well beyond sex. Indeed, one of the opportunities that the internet has provided is the ability to rapidly disseminate information – even when that information is private or inaccurate and its dissemination may be deeply damaging.

awkward interactions with people, so I'm very up front. My HIV status is on my profile – that filters out most negative guys. I don't worry about people knowing my status. Anyone who googles me can see my HIV status – it's no secret.' The advantage of this online 'weeding out' – for everyone – is that it's done at a distance, rather than in an awkward, face-to-face conversation.

What's the point of knowing all this? The standard refrain in internet research is that studying online culture is important in order to develop effective prevention and education materials for the internet. The idea is that HIV prevention and education can somehow insert itself into these conversations. One study of online sexual health promotion found 178 online interventions of different kinds, though many of these were limited to establishing an online 'presence' for the organisation, such as a website or Facebook page.<sup>6</sup>

Australian HIV researchers and educators are increasingly focusing on HIV prevention in online spaces, through websites such as [www.gettested.com.au](http://www.gettested.com.au) or VAC/GMHC's [www.top2bottom.org](http://www.top2bottom.org). ACON, for example, was also involved in the production of the 'Horizon' web series, which featured safe sex themes and was a surprise hit. However, the few guys I spoke to were oblivious to HIV prevention online, 'I have never noticed anything,' said Sam. 'On the other hand, maybe I screen it out because I'm positive and I think, "Oh, I already know that stuff."'

The problem with health promotion campaigns online – as indeed with all health promotion campaigns – is that it is very hard to measure how well they work. Some studies have found online campaigns to be just as effective as campaigns that use more traditional media, but there is mixed evidence on this.<sup>7</sup> For example, the Burnet Institute conducted a research project using emails and text messages to promote sexual health. It was effective in increasing awareness of STIs, but had no impact on condom use.<sup>8</sup> Clearly, HIV education campaigns online need

to be carefully designed and targeted.

Stigma directed toward people living with HIV is one target for HIV education efforts. James suggested focusing on site owners, to encourage them to clamp down on bad behaviour online. 'Spewing someone's HIV status all over the place is not OK. Gay sites need to get serious about responding to that kind of thing,' he says. One study by the US Stopaids group found gay website owners strongly support health promotion efforts, but the report did not address HIV-related stigma at all.<sup>9</sup> Efforts to address stigma have to date been disappointing, though the 'Fear Less, Live More'<sup>10</sup> campaign by AFAO and NAPWHA and the 'ENUF'<sup>11</sup> campaign by Living Positive Victoria are two honourable exceptions. Reducing the stigma attached to HIV should make some of these awkward interactions – whether they are online or anywhere else – a bit easier, but that is no small task.

*Some of the names used in this article have been changed to protect the privacy of individuals.*

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One study by the US Stopaids group found gay website owners strongly support health promotion efforts, but the report did not address HIV-related stigma at all. Efforts to address stigma have to date been disappointing, though the 'Fear Less, Live More' campaign by AFAO and NAPWHA and the 'ENUF' campaign by Living Positive Victoria are two honourable exceptions.



Judith and Roy (2011). Photograph by Dom Gili, a former Ankali volunteer who created a series of photographic works documenting Ankali client volunteer relationships.

## The business of relationships: The Ankali Project

By **John William Jones**

‘Being an Ankali volunteer is a journey full of surprises. There have been moments of intimacy and times of frustration and everything in between. My most important discovery was that just being there was not enough. I had to earn my client’s trust. This journey has enriched my life.’  
– Ankali Project volunteer

For almost 30 years now, Ankali volunteers have been providing social and emotional support to people living with HIV/AIDS. Over the years, the nature of that support has changed in accordance with the changing needs of people living with HIV. In today’s world of highly effective HIV treatment, relative wellness and the prospect of ending HIV transmission, the Ankali Project has evolved and continues to be relevant.

The first Ankali volunteer training took place in May 1985. Before the advent of effective treatments, volunteers were most often matched with clients that had been diagnosed with an AIDS defining illness, and who would possibly die in the very near future. These days it is unlikely that volunteers will be matched with clients who may soon die, let alone from an AIDS defining illness.

I have been a social worker at Ankali since 2003 and the energy and motivation of our volunteers, and seeing the contributions they make to the lives of our clients, continues to sustain me. I have noticed over the years that while the demographics of volunteers change, their motivations and intentions remain the same. When we ask volunteers what motivates them to join the project, they invariably say that they want to give back to the community. Compared to ten years ago, there are fewer gay men who volunteer with the project and more of a cross section of the community, including women, younger and older people and those who don’t necessarily have an existing association with gay or HIV-positive communities.

### First steps

A volunteer’s experience with the project starts with attending four

days of training. Over time, the content of the training has changed to adapt to the changing needs of our clients. Today, there is more of an emphasis on providing volunteers with information and skills on how to manage relationships with people living with mental health issues and people with alcohol and other drug problems, and how to deal with clients who experience the complications of chronic social isolation. Volunteers need to develop skills in setting healthy and realistic boundaries, or relationship rules, with clients.

Upon completion of the training, volunteers commit to attending an hour-long peer support group each week, to give and receive support and supervision regarding the relationship they are having with their client. The support groups are a good opportunity for the volunteer to discuss and debrief about their experiences and get support from fellow volunteers, group leaders and professional staff. Support groups also serve the secondary function of providing a social outlet that helps connect an otherwise diverse group of people who happen to share similar values. Ankali has very good volunteer retention; 25% of volunteers have been with the project for five years or more.

### Structuring supportive relationships

The Ankali Project has approximately 150 clients and the same number of volunteers at any one time. Volunteers are matched to a client on a one-to-one basis and can provide up to five hours of support in any given week. These days, most clients require around two-three hours of support.

The work of volunteers is now largely social, but the nature of emotional support means that it is difficult to distinguish between the social and emotional. The volunteers are trained to be able to provide a non-judgmental listening ear. An Ankali volunteer doesn't judge or give advice, but rather, lets the client take charge of their own decisions.

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### Roy and Judith's story

**Roy and Judith are an Ankali client and volunteer pairing introduced to each other by the project in August 2005. They have continued to meet and chat regularly ever since. Their relationship is typical of many present day Ankali partnerships, where the client is relatively well, yet still values the relationship with their volunteer as unique. As Roy explains: 'I am able to confide in her if I am unwell, and it is different than talking to a friend. Judith, being my Ankali, is able to relate more and understand how I am travelling.'**

Roy says that, like all relationships, their relationship hasn't been without its challenges: 'In the early days it was hard to get (Judith) to laugh, but that changed and we get on tops – she is very, very good!' Although Roy and Judith get on well, they each prefer to maintain the boundaries of the relationship as an Ankali relationship.

Judith continues to get support through the weekly support group and Roy is reviewed routinely by one of the project's social workers to ensure the relationship is as he wants it to be. Judith reports that, 'Roy is an interesting man and it is fun listening to him. Roy is a nice and friendly person to catch up with and have coffee and a laugh. The group support is great, and it is terrific to have such lovely social contact'.

Pictured: Judith and Roy (2011). Photograph by Dom Gili.

The most common activities undertaken by volunteers and clients include social outings such as meetings in cafes, walks to the park, visits to art galleries or trips to the movies. This is in stark contrast to the early days of hospital and hospice visits, conversations about life and death, and supporting someone through the dying process.

The policies of the project go some way to providing structure and support to the relationships that are set up. Clients and volunteers are expected to pay their own way for coffee, meals and activities. This often restricts what activities are possible, but also encourages creativity in coming up with shared activities. Money is not the only issue that can cause tension. Problems can arise if volunteers have plenty of free time and want to spend large amounts of this time with their client. Likewise, the client may be insistent on paying for coffee and lunch. Both of these issues require management in order to sort out the expectations and intentions of both the individuals, and ensure the needs of the client remain paramount.

Clients of the project are assessed by Ankali's professional staff and matched with volunteers based on their need for support. Clients are given an opportunity to express their preferences for the gender, sexuality, age and personal qualities. The matching process aims to provide the client and the volunteer with the best chance of being compatible with the other person. The needs of the client are paramount.

Six weeks after the initial match, a phone call is made to the client to assess how the relationship is going and whether they feel comfortable with the volunteer and that it is meeting their needs and expectations. Following this, a formal face-to-face review is conducted every six months to ensure the relationship is still delivering what the client needs, and that both the client and volunteer are happy to continue.

In a perfect world, Ankali would not need to exist, but in a society that does not provide equal access or equitable resources and support to all, there is a

need for the project. As long as social isolation and stigma continue to be issues for people living with HIV there will continue to be a purpose for Ankali. The fact that clients are still referring themselves to the project, or being referred by their other healthcare workers, is evidence of the project's ongoing need. And the fact that volunteers are still prepared to give their time and efforts to people who, because of their diagnosis with HIV and experiences of living with the virus, require extra support to manage their lives, ensures the project's ongoing success. The work continues.

*The Ankali Project is a division of The Albion Centre, within the South Eastern Sydney Local Health District. For further information about the project visit: <http://thealbioncentre.org.au/>*

**John William Jones is a Social Worker for The Ankali Project at The Albion Centre.**

## Do you have a sexual partner of the opposite HIV status?

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This study has been approved by St Vincent's Hospital (ref. no. HREC/11/SVH/170), Alfred Hospital (ref. no. 80/12), and the Prince Charles Hospital (ref. no. HREC/13/QPCH/70) Human Research Ethics Committees. Version 1.0, 26/03/2013.





# Net-positives: the value of networks and social support for women living with HIV

By **Jayne Russell**

Australia has a comparatively low HIV prevalence rate (115 per 100,000 of the population) with over 80% concentrated in the sub-population of men who have sex with men (MSM).<sup>1</sup> In 2009, an estimated 10–12% of MSM in Australia were living with HIV.<sup>2</sup> Given this concentration, prevention programs have been consistently targeted to MSM via localised gay community organisations, venues and media; however, this focus has meant that there is a paucity of HIV-related services, knowledge and experience of HIV in the general population.<sup>3</sup>

Women living with HIV constitute less than 10% of the HIV population.<sup>4</sup> These women largely reside within the broader Australian population with understandings and meanings of HIV informed through the negative stereotypes and discourses of blame that have characterised people living with HIV in Australia since the beginning of the HIV epidemic.<sup>5,6,7</sup> In addition to being numerically marginalised, women living with HIV in Australia are demographically diverse<sup>8,9,10</sup> and are more likely to live in regional and outer suburban areas.

These factors have implications for service provision.<sup>11,12</sup> In terms of

medical services, women use different healthcare services to men for HIV and non-HIV care<sup>13</sup>: they require gynaecological services for themselves and healthcare services for their families that are likely to be unfamiliar with HIV<sup>14,15</sup>. Furthermore, unwanted disclosure of HIV and unfavourable treatment by healthcare staff have been found to limit the opportunities for women to engage positively with services – both HIV services and mainstream health care.<sup>16</sup>

These barriers mean that women with HIV are unlikely to know other HIV-positive women. In addition, despite facing added layers of HIV-related stigma and conflict in everyday and healthcare settings, and despite difficulties accessing HIV services, the needs of women with HIV attract inadequate resources for intervention and support strategies. This is of particular concern given that physical health can be seriously compromised when an individual's access is restricted to smaller and less diverse social networks<sup>17</sup>, and there is a strong case to strengthen intervention and support strategies that assist in building resilience in the personal networks of HIV-positive women.

## **Social support, social relations, HIV disclosure and social networks**

For women with HIV, partners, children and family members are the most likely important sources of social support.<sup>18</sup> These social relations bring different sets of expectations and obligations<sup>19</sup> and are related to social support and positive health outcomes for HIV-positive women<sup>20,21</sup>. For example, having young children had a positive effect on HIV medication adherence whereas having an HIV-positive husband had a negative effect.<sup>22,23</sup>

Importantly, social support and positive health outcomes are contingent on disclosure of positive HIV status to a range of network members: participants of the Australian HIV Futures Six survey rated their sources of support as more supportive if they had disclosed their positive HIV status to them.<sup>24</sup> Other studies have found that social support was associated with disclosure to friends but not to family<sup>25</sup>; to network members who are believed

*continued overleaf*

to be HIV-positive<sup>26</sup>; to intimate partners, followed by friends, with family the least likely to be told<sup>27,28,29</sup>. However, not all social relationships are positive. Negative social interactions are consistently and strongly related to negative health outcomes.<sup>30,31,32,33</sup>

Social relations between individuals are also the building blocks of social networks<sup>34</sup> that in turn influence social support<sup>35,36</sup>. Social network analysis is the systematic approach to understanding and illuminating the otherwise unobservable patterns of connections between people that give rise to network phenomena.<sup>37,38</sup> Network phenomena produces network effects above and beyond the sum of the effects of the individuals in the network.<sup>39</sup>

## My PhD research

My PhD research project explores the value of network effects and positive and negative social supports within various networks of women living with HIV. Networks where everyone knows each other reflect a closed network – this type of network can produce trust and coordinated action for support amongst the network members but equally produces pressure to conform and restricts access to diverse social resources.<sup>40,41</sup> Alternatively, networks with no connections between network members reflect no potential for coordinated support from others, but do maintain control of social information such as HIV positivity.

Networks with some, but not full connections, link people from outside the network with new information that is otherwise not available within the network and also permit some coordination of resources and trust.

To conduct my research, I travelled to three Australian states in 2009 and 2010 and interviewed 60 HIV-positive women, most in person and a few by phone. The interviews ranged from 30 minutes to three hours. I collected detailed data including demographic, HIV and general health information

in two self-reporting questionnaires and social network data by structured interview. For the social network information I asked each woman to nominate up to 12 people important to them who they had been in contact with in the past month. I then asked for information about each nominated network member, the type and content (including conflict and social supports) of relationships that they had with each of these network members and the type of relationship and extent of conflict, if any, that the network members had with each other.

The demographic diversity of the population of women living with HIV in Australia was reflected in the 60 women I interviewed. They ranged in age from 22 to 70 years with a median of 40 years of age; 57% were born in Australia and 43% overseas including nine from African countries and three from South East Asian countries; 22% had a university level education, a quarter had not completed secondary school, with the remainder having some level of qualification; 45% reported professional occupations, 32% unskilled and 23% reported no profession; 42% were working, a third were not and the remainder were either studying or engaged with home duties full-time. Just over half these women reported very good or excellent health and fewer than 50% reported poor, fair or good health; the time since HIV diagnosis ranged from six months to 27 years (average = 10 years), one quarter had been diagnosed with AIDS and 12% reported a history of hepatitis C.

The 60 women interviewed nominated a total of 467 network members; 60 of these were less than 18 years of age. Of the 467, 40% were family members, 29% friends, 15% healthcare providers, 12% intimate or ex-intimate partners and 4% were co-workers. The networks ranged in size from three to 12 network members (average = eight) and they ranged in density from 0.084 (almost no connections between the network members) to one (100% of network members knew each other). The average density was 0.6 (60% of network members knew each other).

## Case study

This study participant was between 30–49 years of age and had recently migrated to Australia. She worked part-time, and received additional income support from the government. She was diagnosed with both HIV and AIDS in regional Australia six months prior to the interview. This participant reported good health with no other illnesses.

Of the nine network members, there were three women healthcare providers, three women friends, one male HIV-positive peer and two family members (sister and mother). The sister and mother knew each other and the healthcare workers knew each other; all the others were only connected to the study participant. However, there was no support given by the family members.

This network was homophilous<sup>42</sup> with regards to ethnicity and gender: except for the healthcare workers, all network members were of the same ethnicity and except for the HIV peer, all network members were women. Of note, this participant had recently migrated which is associated with ethnically homophilous networks that have limited access to diverse social resources.<sup>43</sup> Because of this ethnic and gender homophily, the social interactions in this network will be more predictable which is important in times of crisis.<sup>44</sup> However, access to diverse social opportunities and interactions is limited but offset to an extent by the healthcare workers.<sup>45,46,47,48,49</sup>

Also evident in this network, was the role of social support as an incentive to the disclosure of HIV-positive status and alternatively, conflict as a disincentive to disclosure. Two of the network members unaware of the participant's HIV positivity were friends. One was a five-year friendship with weekly contact, a lot of conflict and no support; the other participant had known the participant for one year and was in regular contact; there was no conflict but also no social support. Additionally, family members provided no support in this network. The participant received no social support

from her mother and sister and she reported conflict with both of these relationships although she provided them with emotional, informational and practical assistance.

Overall, maintaining these family relations was a burden and negatively impacted the total amount of social support this study participant received from her personal network.

## Summary

This study illustrates how individual and HIV health characteristics, network factors, patterns of disclosure of HIV positivity, the type of social relation and negative relating shape women's experience of living with HIV – particularly opportunities for social support. Having regard to these network characteristics in development of HIV and mainstream health services may provide a way to increase equity and facilitate social wellbeing for women living with HIV.

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Nursing staff on Ward 17 South in 1987 or 1988. Photograph courtesy Colin Clews.

## Life during wartime: nursing on the frontline at Ward 17 South at St Vincent's Hospital

By **Paul Van Reyk**

A paper presented to the Australian Homosexual Histories Conference, Melbourne University, 15–16 November 2013.

### Introduction

*This ain't no party, this ain't no disco,  
this ain't no fooling around  
I'd like to kiss you, I'd love to hold you  
I ain't got no time for that now.*

– *Life During Wartime*, David Byrne.

In October 1983, Ron Penny, Associate Professor in Immunology at St Vincent's Hospital, Darlinghurst, diagnosed the first case of AIDS in Australia.<sup>1</sup> The man was admitted under Penny to Ward 7 South of the Cahill Building, the Immunology ward. Over the next two decades the ward, later redesignated Ward 17 South, arguably was to bear the brunt of hospital care for people with HIV/AIDS.

This paper is part of a wider project to document the history of this and other dedicated AIDS units in the Australian hospitals. The paper focuses on the nursing staff and hopefully goes a small way to redressing the lack of

their voice in Australia's AIDS history. It covers the period 1983–1993 from the first AIDS case in Australia to the beginning of trialling antiretrovirals, the period during which the nursing practice was at its most challenging by all accounts.

### The ward

At the time of the first intake of people with AIDS, the ward was shared between vascular patients at the Northern end and immunology patients at the Southern end. There were 36 beds in all; five six-bedded bays and six single rooms for patients needing intensive nursing or infections requiring isolation. The first people with AIDS treated on the ward were allocated the single rooms. This was because there was little knowledge about the routes of transmission outside of sexual bodily fluids at the time and there were concerns about

the risk of infection to the other immune-compromised patients.<sup>2</sup> As the numbers increased, a six bed bay was added. The single rooms continued to be used for those needing the most intensive nursing, often the dying, and also for women as there was never a sufficient number of women with AIDS at any one time on the ward to be able to allocate them a six-bed bay. Over the next ten years all the beds were allocated to people with AIDS.

Increasing the bed numbers was resisted for some time by the hospital administration for two reasons. The first was the pressure put on other units in the hospital by increasing the intake of people with AIDS, including Emergency and the existing hospital hospice capacity.<sup>3</sup> The second was discomfort among hospital administrators and some surgeons with homosexuality, in part because St Vincent's was a very prominent Catholic institution, and in part from homophobia *per se*.<sup>4</sup> This failure to open more beds despite the availability of additional funding from the State Government as the focus of ongoing community anger.<sup>5</sup>

Some pressure on beds was relieved with the establishment of AIDS units at Prince Henry Hospital, Little Bay, in 1986 and at Royal Prince Alfred Hospital, Camperdown, in 1988 and the opening of the Sacred Heart Hospice with a dedicated AIDS floor in October 1998.<sup>6</sup>

More beds were finally opened in August 1989.<sup>7</sup> From the early to mid-1990s the ward was at full capacity of 36 beds constantly.

St Vincent's also ran an AIDS outpatient clinic beginning one morning a week (Friday), increasing to five days a week in December 1988.<sup>8</sup> The Maitraya Day Centre was established by St Vincent's and Darlinghurst Community Health Centre in November 1987 beginning one day a week and also increasing to five days a week in December 1988.

## The nurses

*I think why the ward had such a good reputation was because the nursing*

*was so good. The nurses we attracted did it because they wanted to. There was a strong empathy between the nurses and the patients. But they were very professional also. I don't think any boundaries were crossed.*

– Professor David Cooper

Who were these nurses of whom Cooper speaks so highly?

*I had seen (Ward 7 staff) in the cafeteria and I thought, these people are full of love, they're out there, they're queer and if they are not they are queer friendly and I was queer and coming out. I want to work with these people.*

– Anne Maree Sweeney, Registered Nurse and Clinical Nurse Specialist.

Many were gay men and lesbians who wanted to 'take care of their own'; friends, their wider social network, their community, sometimes their partners. Some of them were themselves positive. Others were heterosexual men and women who also had friends or relatives who were people with AIDS, or who saw AIDS as a health crisis to which they wanted to contribute their nursing skills and wanted to do this alongside 'like-minded' people.

Not unexpectedly, the ward had a higher proportion of male nurses than other wards in the hospital, at times as high as 50%. Most of them were of the same generation as many of those they cared for. Some had been nursing for some years in oncology, paediatrics, critical care, respiratory illnesses or psychiatry. For others it was their first nursing experience. There was a lot to learn. Many of the presenting illnesses were rarely seen and certainly not in the young population they were dealing with. Treatments for these, and the later antiretrovirals, were experimental and knowledge of their efficacy and side-effects were only learned from observing the results of treatment.

The nurses also learned new nursing skills when other specialist staff refused to deal with people with AIDS, like having to take blood for culturing or inserting canulas because pathology staff wouldn't. Much of this learning was done at the bedside working with

what they all describe as a genuinely collaborative multidisciplinary team, one which was not 'doctorcratic' and which encouraged questioning, critical incident de-briefing. This was supplemented through ward meetings and regular in-services. Some were supported to undertake the Sydney Hospital six month Post Graduate course in HIV/AIDS established in the early 1990s.

Later, Moys Gillespie recalls, new nurses would learn about the treatments, their doses and side effects from people with AIDS themselves.

*The guys taught you. They knew their meds back to front. You'd take the drug trolley around and there'd be lots and lots. But the guys would say to you I need that and that. That was my first example of patients taking control of their own health in terms of questioning. It took a little bit of getting used to but I thought it was amazing.*

– Moys Gillespie, Registered Nurse and Clinical Nurse Specialist.

In sum, in the words of ex-Nurse Unit Manager (NUM) David Crawford they were all 'very skilled, very caring, and very driven.'

But then, you had to be to survive life in the war zone.

## The war zone

*It was like working in Emergency every day. 'So and so's just stopped breathing. Grab the CPAP. Hang the bags. Put a line in. Try and get a doctor down as soon as you can.' While that's happening three guys in the same bay are having diarrhoea that's non-stop or intractable vomiting. Bleeding, bubbling lungs. Everybody was on oxygen ... Top to toe nursing. There was a lot of screaming. Dementia. And everybody was dying.*

– Anne Maree Sweeney

Nursing was constant and physically exhausting. Everyone remembers the cryptosporidium diarrhoea, not shit so much as brown water, sometimes 10 and 12 litres of it a day from a single patient. How thin and frail people

*continued overleaf*

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were; young men who should have weighed 75 kilos down to 35 kilos, for whom lying in bed was agony, who needed to be turned regularly to ease the discomfort, each turn in itself causing excruciating pain. Changing clothing and bed linen sopping from night sweats five and six times a night. The dementia and screaming from those with cryptococcal meningitis or cerebral toxoplasmosis. On other units you might take patient observations twice a day; here you might be taken them hourly. When the hospital introduced its Patient Assessment Intervention Score system to track nursing workload, the figures for the ward were off the chart, says ex-NUM Bill Paterson.

Once diagnosed, opportunistic illnesses were aggressively treated with what was available. Some of it was experimental. Some of it was toxic. Sometimes it paid off.

*In the early days, 80% of the people presented with pneumocystis carinni pneumonia which had around a 60% fatality rate. In St Vincent's we brought that down to 20% because we diagnosed really quickly and treated really quickly. We weren't able to get our patients in to ICU [intensive care unit] so we had to give them ICU care on the ward and didn't have access to highly specialised ICU lifesaving equipment like ventilators. The ICU team was very supportive of our work however and provided a consultation service.*

– Bill Paterson, Registered Nurse and Nursing Unit Manager.

Often the time would come for a difficult conversation amongst the treating team, the person with AIDS and their significant others whether to continue with treatment and when to move to palliation, particularly where it was experimental or the side effects were severe.

*We used to say to people: "We may not get you through this but the investigations we do on you will inform how we treat those who come after". And to their endless honour they would say yes.*

But always there was death: confronting, often painful, sometimes lonely. In the early days people would come in with pneumocystis carinni pneumonia and die within a matter of hours, some in Emergency while waiting for a bed. Later treatments often had a honeymoon period where you could stabilise someone enough to discharge them, but the illness would return or some new illness would appear. People died within two years of diagnosis.

*I think we were all exposed during nursing one way or another.*

– Tina Kelleher, Registered Nurse.

They were always at risk of infection themselves. Barrier nursing, wearing gowns, gloves and masks when dealing with infectious patients, had given way to universal infection control procedures which worked most of the time. But they still got infections like scabies and cryptosporidiosis. Two contracted tuberculosis during an outbreak of it on the ward for lack of adequate facilities in which to do induced sputum. Needle stick accidents were common but led to HIV infection in only one case. At the same time surgeons in Australia were pushing for \$5,000 spaceman like protective suits, for testing all surgery patients, and for the right to refuse to operate on anyone who was HIV-positive, a push firmly rejected by all Ministers of Health at Federal, State and Territorial level.<sup>9</sup>

But nursing was about more than physical care. Much of it was accidental counselling of people with AIDS (PWA), their partners and friends, their families. A lot of it was advocacy for their patients: getting a reluctant Registrar to attend after hours; doing whatever the staff in the vascular nursing end of the ward insisted on as protection from imagined transmission so people with AIDS could use the only bath on the floor; ordering family and partners to take their fights over the disposal of property or the right to make treatment decisions out of the ward; evading parents' questions that would disclose their son's sexuality or that he had AIDS; or battling with nursing administrators to get a someone into a streamer bedecked wheelchair, iv drip and all, down to

Oxford Street to view their last Mardi Gras.

*Many of their parents didn't know their son was gay let alone had HIV. I can't think of a single time we slipped up, because we weren't lying. You know, "Your son's dying of pneumonia. Yeah, it's unusual but it's happening".*

– Tina Kelleher

Whatever it took to make the person with AIDS comfortable was done; rules were broken. A watch was kept for the nursing administrator while someone smoked in the fire stair. Couples would lie in bed together behind closed doors or curtains with no questions asked of how far intimacy went. At least once a dog was smuggled in to comfort its dying companion human. Clean needles were discreetly passed. Condoms were palmed.

Discrimination from colleagues and surgical staff was not uncommon though often veiled. Your sexuality and motivation were fair game for gossip.

*A lot of us were gay men and there was a predominant feeling from other nurses that we were there because we were HIV as well. They felt we were over involved with our patients. There was a bit of our patients got what they deserved because of their lifestyles. They said we were blurring our boundaries.*

– Bill Paterson

*I got asked why on earth I would want to go and work on that ward. They made the assumption that I was gay.*

– Moys Gillespie

David Crawford talks about feeling like NUMs of other wards resented what they saw as too much money and resources going to people with AIDS in the hospital:

*But the ward was not unremittingly grim. You could count on drag queens turning up in a flurry of feathers and sparkles to do an impromptu show. The Friends of Seventeenth South would play Santa or the bunnies and angels from Hop Yourself Stupid would turn up with Easter eggs for all.*

And always there were the people with AIDS and their partners and friends

being defiantly outrageous and taking the piss out of you.

*So I walk in to the 1st single room on 17 South to meet Aldo, early days so he's as skinny as, "Bill, Bill" he says to me, "feel my back!" I feel his back, all skin and bone – shoulder blades sticking out a mile. Of course the weight loss gave him a smile the size of the Sydney harbour bridge. "Yes Aldo" I said stroking his back "I can feel your bones". "Oh no, Bill" he says, "those are my wings growing" and my heart opened a little wider.*

– Bill Paterson

*You would walk into a six bedded bay and it was like a party was going on. There was a lot of laughing. A lot of noise. A lot of flirting. You had to come and show them what you were wearing to the dance parties. They used to think it was hysterical when you would come in the morning and they knew you hadn't been to sleep.*

– Tina Kelleher

## Coping

Still, the emotional toll was high.

*Coming to work was always confronting. There were lots of people I knew by sight, by name, knew personally. It was uncommon that there wouldn't be each month someone coming on to the ward that I knew getting ill and dying ...*

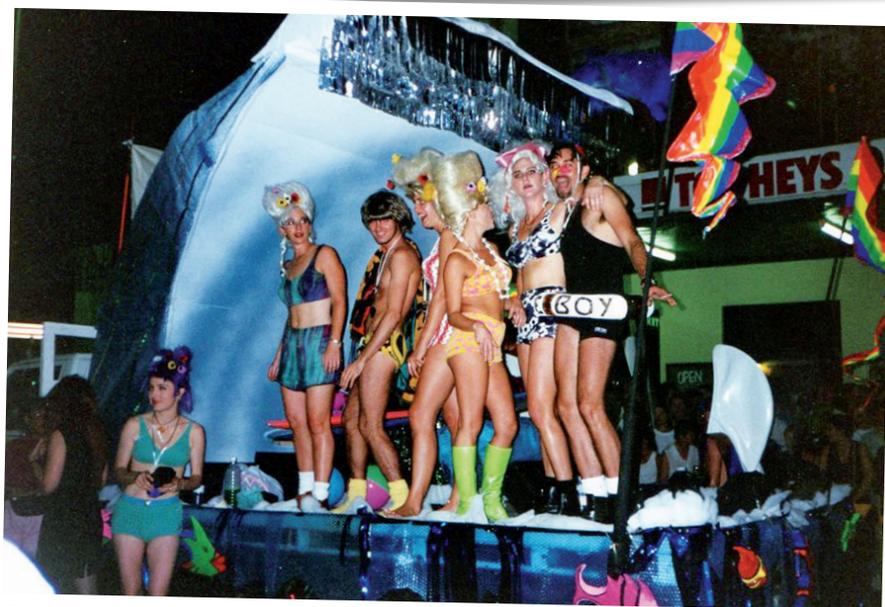
*You had to have a distance, an emotional cut off because if you became emotionally involved with everyone you wouldn't last.*

– Robert Fieland, Registered Nurse.

In the early years, estimates Bill Paterson, the average term on the ward was three months, some leaving after finding that this nursing was not for them, most through burnout.

They dealt with it through largely through looking out for and after each other and with drinking, drugging and partying together.

*We'd live at the Albury Hotel and the Green Park Hotel. And at each others houses. We'd hang out together. Do anything that would make us happy. Watch Marilyn Monroe movies together. Go to the beach. We cried on*



**Pictured top:** Bill Paterson and Roger Nolan in the treatment room at St Vincent's. Photograph courtesy Bill Paterson; and **above:** Ward 17 South's 1993 Sydney Gay and Lesbian Mardi Gras Parade float. Photograph courtesy Jeanette Atkinson.

*each other's shoulders and we sat on each other's laps.*

– Anne Maree Sweeney

For some, partners provided support. For others, family was often not supportive, either because of homophobia or because they saw the person as wilfully putting themselves in unnecessary danger. There was a staff counsellor available and later also the unit's dedicated social workers, but they rarely accessed them. A support group started by David Crawford didn't succeed, in part, he says, because people thought they were managing okay even when they weren't, but also because they just didn't want to talk about it.

For gay men and lesbians living and socialising in the communities being known as working on the ward had its good and bad sides. On the good side, people would come up to them and thank them for the care they provided their partner, or friend; they could always count on being shouted a beer. They could be cheered as they boogied on the 17 South Mardi Gras float even if they weren't allowed to have St Vincent's name on it. Or they could release their inner drag queen at DCMs and do a number choreographed by Kristy McNicol and raise funds for the ward.

*continued overleaf*

On the downside it could be hard to leave work behind. It could take you a long time to walk a block on Oxford Street as people would come up and ask about friends on the ward or want to talk about AIDS and treatments and prognoses. They developed strategies for avoiding this and for not breaking the confidentiality of those they were caring for.

What was harder to take was bearing the brunt of community anger at people staying 48 hours in Emergency for lack of beds on the ward.

By the mid-nineties changes to the pattern of illness and nursing supports put in place by successive NUMs to deal with the emotional and physical impact had lengthened the average stay to two years and many continued longer. Staff to patient ratios had increased as a result of determined lobbying based on rigorous completion of the Pathology Analytical Imaging Standards (PAIS) data.

## Finale

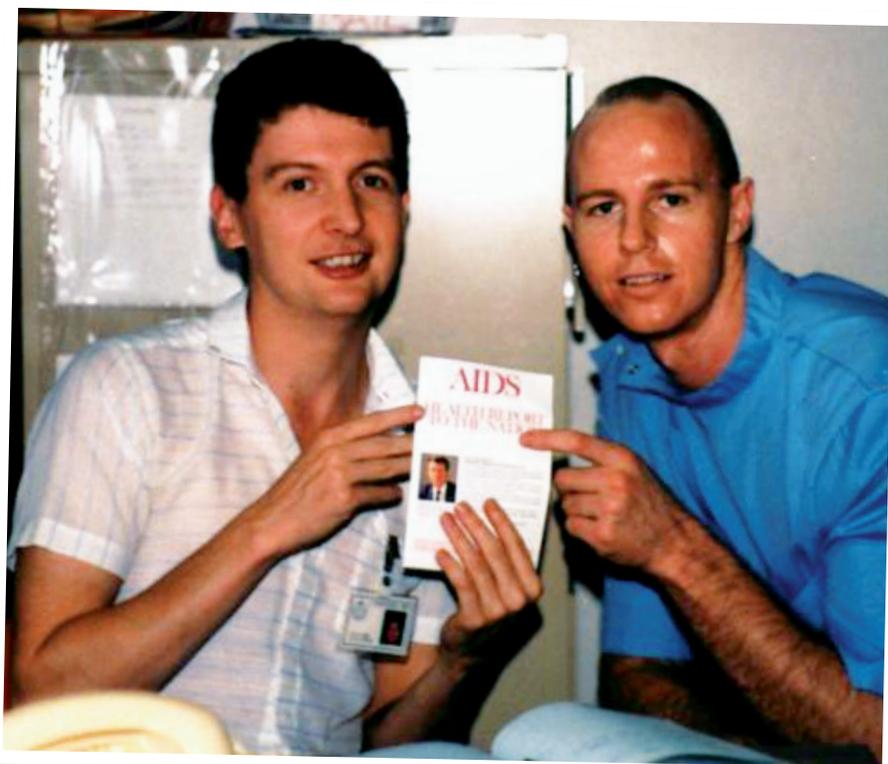
In November 2007 St Vincent's announced the AIDS unit had closed. Advances in antiretroviral and other treatments had resulted in fewer in-hospital bed days for people with AIDS. Since the late 1990s the beds had been increasingly re-allocated for other illnesses and people with AIDS were mainstreamed into the general or other specialist wards.

*I think we excelled ourselves. We used to say to nurses on other wards who used to get snippy – 'Don't drag us down, pull yourself up'.*

– Tina Kelleher

## Thanks

I thank the nurses who over the years cared so excellently for my dear friends and who unsparingly shared their stories with me for this paper: **Suzi Aboud**, Registered Nurse 1989–1992; **David Crawford**, Registered Nurse 1989–1992, Clinical Nurse Specialist 1992–1993, Nursing Unit Manager 1993–1998; **Robert Fielden**, Registered Nurse 1989–1993; **Moys Gillespie**, Registered Nurse, Clinical Specialist 1993–1998; **Bill Paterson**,



Social worker Colin Clews and wardsman Graham, St Vincent's Hospital Ward 17 South. Photograph courtesy Colin Clews.

Registered Nurse 1986–1989, Nursing Unit Manager 1989–1993; **Ann-Maree Sweeney**, Registered Nurse 1989–1992, Clinical Nurse Specialist 1993–1996.

I also want to thank all the contributors to the Ward 17 South Connection Facebook page whose postings I have drawn on also; Professor David Cooper who continues to be a remarkable human being; and *The Sydney Star Observer* for giving me open access to their archive.

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- 2 Professor David Cooper interviewed for this paper, 2013.
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**Paul van Reyk has been an HIV/AIDS activist since 1983. He was the first full-time Policy Officer for ACON, during which time he developed a carer handbook for Community Support Network (CSN), the booklet *Choosing to Die*, and wrote the ACON response to the Baume inquiry into the approval of treatments in Australia. Most recently, he was worked with PLWHA organisations in Papua New Guinea.**



Liz Crock and John Hall at the VAC/GMHC stall at Midsumma, 2014

## Unlikely bedfellows: an enduring relationship between two organisations

By **Liz Crock** and **John Hall**

The Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC) and the Royal District Nursing Service (RDNS) have had a formal partnership in place for the past 23 years, and more importantly, have worked together to support people with HIV for 30 years.

This partnership between these two Melbourne-based organisations remains a world first model of

integrated community-based care and support, advocacy and health promotion for people with HIV, their significant others and volunteers, and is an easily accessible point of expert contact for sector staff.

RDNS is a community nursing organisation established in 1885, to treat 'the sick poor' in their own homes.<sup>1</sup> Victorian AIDS Council/Gay

Men's Health Centre (VAC/GMHC) is a strong, diverse community-based organisation, which formed in 1983, born out of the gay community's social and political activism in response to the imminent threat of what was then called GRID (Gay Related Immune Deficiency).

*continued overleaf*

Although RDNS and VAC/GMHC may seem to be 'unlikely bedfellows', the fundamentals underpinning both organisations' philosophies and practices were aligned: an expressed commitment to client empowerment, a focus on social justice, access and equity in regard to healthcare, information and education and a commitment to human rights. These shared values and principles ensured that an effective and enduring relationship could be nurtured and would endure the test of time.

### Coming together: a marriage of convenience

The first RDNS HIV patient was cared for in 1985 by a nurse who had taken a personal interest in HIV/AIDS and undertaken self-education, thus it was not initially an organisational response. Since 1986, RDNS has had a specially funded HIV Program.

RDNS Director of Nursing, Norma Bryan, took the lead, ensuring that education was available for the nurses and their families to allay fear and promote a professional approach to this devastating epidemic. Three specialist nurses initially cared for all HIV and AIDS patients in their region. These nurses already had regular contact with VAC/GMHC's Support Program workers and volunteers, before the formal partnership was established. As numbers grew, in 1988 the 'AIDS Nursing Program' was integrated into the mainstream nursing service at RDNS.

During the early years of the epidemic, RDNS was integral in training VAC/GMHC volunteers in home-based care, infection control and supporting people to die at home. This occurred during a time when public ignorance – and sometimes political hostility – was rife, so the stage was set to forge new relationships within the sexual politics context.

In 1987, the Victorian Department of Health had recommended integration of RDNS' HIV Program and VAC/GMHC. The structures of VAC/GMHC, covering three main regions,

(North/West, Eastern and Southern) with links to regional HIV support groups, were aligned with RDNS' regions. Over time, these links opened the door for shared clients to engage in broader health and wellbeing options at VAC/GMHC, including counselling, GP services (HIV, sexual health and lesbian, gay, bisexual, transgender and intersex [LGBTI] health), peer education, peer support, health promotion initiatives, financial and legal services, as well as referral to partner agencies.

Our family of partner agencies expanded beyond clinical and community connections to the Prostitutes' Collective (now RhED), Vivuids (now Harm Reduction Victoria), GAMMA (Gay and Married Men's Association) and transgender groups, to name a few. These groups soon became active in VAC/GMHC's training and education schedules due to the perceived 'at risk' status of people they represented. Once you hopped into the collective services bed with VAC/GMHC, one could find themselves in a world of intriguing companions.

The path to unlikely, but perfectly matched bedfellows was well and truly established.

### Formalising the engagement

Following the recommended 'marriage of convenience' initiated by the Department of Health, a position paper *Home care for people with AIDS in Victoria*<sup>2</sup> led to a pilot project being undertaken in 1988.

Key elements of an integrated service model were identified in the project, many of which are still central to the partnership today. These included: making appropriate use of existing resources through integration of flexible and trained volunteer labour; professional and accessible nursing care; catering for people at diverse stages of HIV infection; providing the best quality care and expertise; service user input and participation in service development; developing a continuum of care; integrating the two services; and regionalising VAC/GMHC support services.<sup>3</sup>

The project consummated the relationship between RDNS and VAC/GMHC and a broad community-based health and wellbeing service was born. In a radical move showing VAC/GMHC and RDNS to be ahead of the ball game, the client empowerment and engagement model pioneered in the project is referred to today as the 'GIPA' principle. The partnership was six years ahead of the declaration of this principle at the 1994 United Nations Paris AIDS summit.

### Relationship dynamics and evolving roles

From the mid '80s to the early '90s, the focus of the VAC/GMHC/RDNS relationship was on providing care around the clock for people who wanted to die at home, or who needed ongoing technical treatments. Many had few family supports and volunteers often took the place of families. VAC/GMHC volunteers were seen as valued and equal partners, often being the 'eyes and ears' for nursing staff, including recording – with the client's consent – observations in RDNS' communication books.

As new treatments became available in the mid-1990s, many more people with HIV survived, yet the need for community-based services has grown. The RDNS HIV Program and VAC/GMHC HIV Services have adapted to meet changing demographics and diverse needs.

In some ways the issues today faced by people with HIV are more complex. Notable changes in the last ten years have included: a greater proportion of women, people from culturally and linguistically diverse backgrounds including refugees and asylum seekers, a range of comorbidities, mental health, alcohol and drug issues, physical frailty and ageing, cognitive impairment and disability. These changes influence both the planning and nature of care. Homelessness and issues relating to poverty are increasingly prevalent amongst people with HIV supported by the partnership.

The skills, knowledge of resources and community linkages required to provide care to such diverse groups pose



**Left:** Volunteers packing food for Tuckerbag Meals project; and **right:** a volunteer delivers Tuckerbag Meals

additional challenges to mainstream services. The relationship between VAC/GMHC and RDNS provides an effective 'early detection' mechanism and pathway to deal with emerging issues such as these.

### Current partnering: the relationship blooms

In 2006, VAC and RDNS entered into a formal Partnership Agreement, which continues to the present day. This agreement incorporates areas of integration and collaboration including education (for clients, volunteers, RDNS and VAC/GMHC staff), strategic planning, joint staff selection committees and health promotion projects. Strong mutual referral pathways exist between the two organisations, including with VAC's clinical services (The Centre Clinic), counselling, and the new rapid testing service, 'Pronto!'

Today the HIV Program at RDNS consists of three regional-based HIV Clinical Nurse Consultants working across metropolitan Melbourne and the

Mornington Peninsula. In recent years additional roles were developed. 'HIV Resource Nurses' are based at RDNS centres in the south, north and west of Melbourne where large numbers of people with HIV reside.<sup>4</sup> In 2010, the (state funded) Hospital Admissions Risk Program piloted additional HIV nursing roles based in hospital settings which enhances communication and referrals, and prevents people with HIV falling through the gaps. One of these new HIV nurses is employed through RDNS, thereby building capacity.

VAC/GMHC has been restructured with a Services Division combining operations at the Positive Living Centre, volunteer activities through Community Support, In Home Support (residential, paid attendant care for clients experiencing complex psycho/social/health issues), Positive Counselling for people living with and those affected by HIV, LGBTI issues, hepatitis C, and other issues, the Centre Clinic and 'Pronto!'

RDNS plays an active role in volunteer and staff orientation and induction

processes and is a clinical resource for these groups. RDNS also advises on changes within the epidemic and emerging issues. An example is the current input into service planning around ageing with HIV being undertaken by Burnet Institute and the Alfred Hospital in partnership with other community groups. RDNS also serves on VAC/CMHC's Research, Ethics and Promotion Committee.

### Parallel epidemics – divergent outcomes

While *most* people are living well with HIV, clearly there are subgroups that are not. This is a fact that is understated and undervalued at many levels, seemingly incongruent to current approaches to health care planning, priorities and funding.

At the height of the epidemic, (pre-HAART) there were several deaths a week. This has decreased dramatically, however we still average one death per month amongst RDNS and

*continued overleaf*

VAC/GMHC clients from HIV-related disease complications (PML<sup>5</sup>, cardiovascular disease, various cancers, liver failure) and even suicide. With the demise of specialist HIV/AIDS bodies in some states and the mainstreaming of care and support in others, it is vital that advocacy for those most at risk of poor outcomes is not lost.

Our Partnership provides the capacity to monitor the situation and advocate on the realities of what the 'chronic' status of HIV really means – often to the discomfort of some within clinical services and peer-based bodies. Depending upon when and where one was diagnosed, what drug regimen one may have experienced and what comorbidities one may have, there can be very different health outcomes.

The Partnership provides a safety net for people with HIV with complex health and psychosocial issues which other services may overlook or with whom they may be reluctant to engage. Sometimes, sub-groups are marginalised even within the HIV sector: these are all priority groups of the national and Victorian HIV strategies. Both RDNS and VAC/GMHC proactively enact the philosophies and goals of the strategies. Fundamentally, it's about social justice, human rights, and equity in health care, all essential for good health outcomes.

### Healthy offspring: health promotion and prevention

Another element of the Partnership that has developed in recent years involves joint projects. In 2010, the HIV team at RDNS observed a growing number of clients with poor food security, low literacy and limited cooking and shopping skills. VAC/GMHC raised funds and 'Tuckerbag Meals' was piloted as a community development and health promotion project, with volunteers providing simple menus, delivering ingredients and materials, and mentoring in cooking skills over a three-month period. Evaluation by three Monash University medical students on a community placement

with the RDNS HIV Team showed greater participation by people with HIV in cooking and engagement with family members, improved skills and confidence in cooking, shopping, and self-esteem.

Since 2011, VAC/GMHC has raised funds from other sources (GLOBE, The Laird Hotel, Ian Potter Foundation, and the National Australia Bank) to sustain 'Tuckerbag'. The program has expanded to include clients from the Horn of Africa, Vietnam and the Middle East, often with children with diverse nutritional needs and preferences.

### The future of the relationship

The VAC/GMHC/RDNS Partnership plays a pivotal role in linkage, engagement and retention of people with HIV in health care.

The role of RDNS in promoting HIV treatment adherence ranges from providing education, reinforcing safe behaviours and coordinating overall care in the community within the Partnership, ensuring treatment access. Volunteers from VAC/GMHC provide transport to medical appointments, socialisation and practical and emotional supports, all central to adherence and the reduction of risk behaviours. These comprehensive and responsive services will serve to empower clients and will contribute to preventing HIV transmission well into the future, and ensure that 'treatment as prevention' can reach those most vulnerable, in the spirit of true equity.

Promoting and assisting in Advance Care planning, including providing ongoing support to those who competently decide not to take treatments, a challenging and controversial topic nowadays, are also important roles of the Partnership.

### The enduring marriage continues

Fundamental to the success of the RDNS/VAC/GMHC Partnership Agreement has been the 'marriage' of good community-based services, with clinical and non-clinical staff, including volunteers, working together

to optimise health and wellbeing for people with HIV.

Although at first glance, a Partnership between a traditional nursing service and a radical, grassroots gay activist organisation at the height of the HIV epidemic may seem counter-intuitive and improbable, the model of care and service delivery developed between RDNS and VAC/GMHC has certainly stood the test of time. Unlike other passionate affairs, it is not fizzling out but is growing stronger, more resilient and responsive to changing needs and dynamics as the HIV sector faces the challenges of the next decade.

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## 'We're all on the same side': relationships between general practitioners and their patients and peers in HIV medicine

By **Christy Newman, Asha Persson, John de Wit** and **Michael Kidd**

Over the last few years, our research team travelled around Australia to interview general practitioners (GPs) about their experiences in providing care to people with HIV. We published a number of articles exploring the motivations of GPs to become and stay involved in this field, whether in providing general health care to people with HIV, or pursuing additional training and accreditation to prescribe HIV medications.<sup>1</sup>

Throughout these interviews, we heard first-hand accounts of how meaningful these GPs found it to play a role in managing the health of patients with HIV. This was not only due to the intellectual challenges of HIV medicine, or the professional opportunities of developing a special interest in HIV and sexual health. Again and again, and across a diversity of geographic settings, GPs told us it was the relationships they had formed over time with both patients and peers that made this a rewarding field of clinical practice.

In this article, we've reproduced some of the quotes on relationships that we have published in the peer reviewed literature

(with full references at the end if you'd like to read more). This is organised this into two main sections, to capture the meanings ascribed to relationships between GPs and their patients, and between GPs and their peers.

### Relationships with patients

In the 'early years' of the HIV epidemic, GPs witnessed the deaths of sometimes very high numbers of patients, as well as friends and colleagues, through AIDS-related illnesses. One of the strategies GPs identified as helping them remain involved in providing HIV care through and beyond those years was to draw strength from their relationships with patients:

*What's actually kept me here, it's the patients ... True, I have my life outside here, which is far more important ... But you wouldn't have stuck around all these years unless ... you were really getting something out of it.<sup>2</sup> (p.736)*

Since that time, GPs have played a central role in responding to the many developments in HIV medicine, and many have pursued the unique opportunity in Australia for GPs to be

accredited as an 'HIV s100 prescriber'. Having the option to provide both general and treatment-related care was viewed as particularly helpful in building close and trusting relationships with HIV patients:

*I'm often the person that will be delivering a diagnosis. And for me it's a privilege to be able to give that diagnosis and then say, "But ... I can help you to look after this and we don't have to send you off to someone else" ... So it can all just be ... like a one stop shop for me, for my patients.<sup>3</sup> (p.8)*

Providing continuity of care was also highly valued by these GPs as this made it possible to build long-term relationships with patients, and 'travel with them' through their different stages of life and the different eras of HIV medicine:

*It's lovely because you sort of grow and age with them and get to know them quite well. Seeing the medications get better and seeing people live much longer than you thought [they] were going to is very rewarding.<sup>3</sup> (p.7)*

*continued overleaf*

This sense of trust and intimacy was seen to challenge the notion that clinical encounters feature an impersonal distance between doctor and patient. On the contrary, the 'bond' with patients reported by GPs in this study was viewed as a distinctive and treasured feature of this field:

*Well, the relationships that you establish with patients that can, that's very special I think ... It's a very personal practice. I mean people let you into their lives and it's extraordinary what they tell you and what you share ... You develop wonderful relationships with people.<sup>4</sup>*

### Relationships with peers

Although general practitioners often work in group practices, and know some of the other GPs working in their local area, it can be challenging to find the time and opportunities to forge professional connections in this field of medicine. For this reason, the GPs who took part in our research greatly appreciated the professional relationships they had formed through HIV medicine:

*I wouldn't know a handful of general practitioners from my area but I know about fifty HIV GPs because we all see each other a lot. And ... that's a very nice part I think. There's a bit of a club feel.<sup>5</sup> (p.8)*

Beyond simply offering an opportunity to expand their professional networks, these connections were seen to offer a sense of camaraderie and shared clinical purpose:

*[I]t's also rewarding to be involved with other health professionals that are highly motivated to engage in an area of challenge and significant*

*difficulty... I think there's quite a degree of collegiality or camaraderie amongst fellow prescribers.<sup>6</sup> (p.8)*

While not all of the GPs we interviewed felt this supported and connected, in most cases the sense of belonging afforded through association with the field of HIV medicine was seen to provide essential motivation and encouragement to remain engaged over time:

*[T]he collegiality of the area is far and away what's kept me in it ... I think it's all a bit of a club and we're all on the same side.<sup>7</sup> (p.8)*

This idea of HIV medicine as a 'bit of a club' encompassed a broader range of health and medical professionals beyond general practice, including the specialist providers contributing to HIV medicine in hospitals and sexual health clinics, and the practice nurses who so often played an essential role in shaping a comprehensive and cohesive community HIV care 'team'.

### Conclusion

In examining the motivations of GPs to provide care to people with HIV over time, relationships were consistently identified as a primary driver, and as a unique feature of this field of practice. While these relationships were described as intimate, providing deep internal strength and encouragement to stay involved over time, they also revealed the value GPs placed on feeling part of a team and of having a sense of belonging with a community of patients and a community of peers.

### Acknowledgements

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Although general practitioners often work in group practices, and know some of the other GPs working in their local area, it can be challenging to find the time and opportunities to forge professional connections in this field of medicine.



## BOOK REVIEW: THE END OF THE HOMOSEXUAL?

By Dennis Altman. Published by  
The University of Queensland Press

More than half way through Dennis Altman's personal account of the gay liberation movement, he observes that, 'In some ways, the central question of this book is whether the glass is half-full or half-empty. Clearly, much has changed since the days of the first gay liberation demonstrations, forty years ago.' He then goes on to quote historian Shirleene Robinson: 'It might be easy to feel that homophobia is no longer an issue for the majority of the queer population, and that the gay and lesbian liberation movement has successfully eradicated prejudices once so strong held ... this is not the case.'

It seems the polymorphous perversity a younger Dennis Altman expected to develop from that movement, rendering homosexuality irrelevant as a primary marker of identity, and recreating us all as undifferentiated sexual beings, has fallen short of expectations. Yes, there is less homophobia in Australia and comparable societies, but 'the idea of a fluid and diverse sexuality that does not need categories is still utopian.'

I grew up in Melbourne and I came out in 1981. Dennis Altman and others in the gay liberation movement at that time helped me to understand the world as it then was, and how it might change in ways that would allow me to be who I was. His writing and activism on gay liberation, and later on HIV, exposed the sometimes unthinking and sometimes hateful oppression and marginalisation that were part of growing up gay at that time.

Forty years on, the issues raised by the movement continue to affect our lives. The term 'gay liberation' may have fallen into disuse, but the ideas it

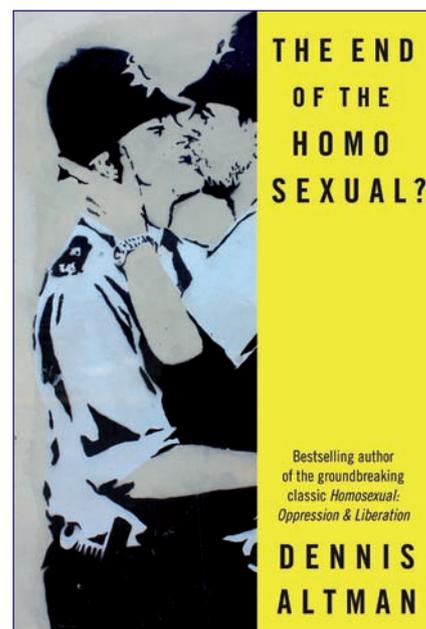
represented have reached forward into the 21st Century with a prescience we have to admire.

The social changes concerning gender and sexuality which have occurred since the 1970s have been momentous and transforming. Dennis Altman's account of his own involvement in many of these changes makes for an engrossing personal and political narrative which reflects much of the experience of homosexual men (and to a lesser extent women) from the 1960s onwards. Perhaps not the part about being invited to Gore Vidal's holiday house, but much of the rest.

The response to HIV in Australia was largely built on the then nascent phenomenon of a visible gay community, within which were established media, advocacy groups, social organisations, and commercial venues. In Altman's view, 'the epidemic brought forth a maturity in policy-making that few would have predicted', and that was matched by few other countries at the time. The 'combination of effective and largely bipartisan political leadership and a savvy gay movement' dealt with attacks on homosexuality and the civil liberties of gay men, denying those attacks any real traction. Many gay men moved from street protests to organisation building, and then into government and international agencies responding to the global AIDS pandemic. 'It became possible to build a career out of one's involvement in the gay world'.

The sense of this book reflecting my own experience was heightened in the chapter 'The 1980s: HIV/AIDS and Working inside the System'. Altman saw a reinvigorated sense of community and political activism among gay men in response to HIV. He reflects on the early 1990s, 'when the first generation of AIDS drugs promised false hope and the gay newspapers were full of obituaries of men in what should have been the prime of their life.' He goes on to say that, 'The impact of AIDS on the generation of men who lived through its first decades was permanent, and it has created a gap in experience between us and younger gay men.'

In a personal narrative that manages to encompass pre-liberation



homosexuality, homosexual law reform, and first-hand accounts of gay liberation movements in Paris, New York City, San Francisco, Tokyo, Brazil, and Bosnia, together with legal and cultural milestones along the way, it may seem churlish to identify gaps. Dennis Altman writes in rather harsh and cursory terms of the current Australian HIV response, which is described as 'its own closed, corporatist world of AIDS professionals,' and in this context quotes William F. Buckley who said that 'every great issue begins as a cause, becomes a movement and ends as a cabal.'

The Australian epidemic and our response to it have both (inevitably) changed greatly since the early 1980s. I would have liked to see a more nuanced analysis of those changes, particularly of the community response and community organisations, in both of which Altman has played a prominent role. Nevertheless, *The End of the Homosexual?* is a very readable book of remarkable scope. And the image of Ita Buttrose, then perhaps the most well-known woman in Australia, sitting at an AIDS conference buffing her nails while she listened to a discussion of anal sex and HIV transmission, is one I will not easily forget.

**Chris Ward is an HIV policy analyst and former manager of policy and international projects at AFAO. He has worked on HIV policy and projects with government and civil society partners in South and South East Asia.**



## TREATMENT BRIEFS

### HIGHER PILL BURDEN IS ASSOCIATED WITH POORER ADHERENCE AND REDUCED CHANCES OF VIRAL SUPPRESSION

Lower pill burden is associated with higher rates of adherence to HIV treatment and better virological outcomes, according to the results of a meta-analysis published in *Clinical Infectious Diseases*. However, the association between adherence and pill burden was only significant for twice-daily combinations. Although adherence to once-daily regimens was better with compared to twice-daily treatment; once-daily therapy was not superior to twice-daily treatment in terms of virological suppression.

A total of 19 studies including 6,312 people met the inclusion criteria. The studies were conducted between 2004 and 2011. Most (18/19, 95%) were published in peer-reviewed journals. Higher pill burden was associated with lower rates of adherence ( $p = 0.004$ ). But when the results were stratified by treatment strategy, the association between adherence and pill burden was only significant for twice-daily combinations ( $p = 0.001$ ). There was also a significant association between higher pill burden and reduced chances of achieving virologic suppression ( $p < 0.0001$ ). This was the case for both once-daily ( $p = 0.005$ ) and twice-daily ( $p = 0.0003$ ) regimens.

Adherence was higher with once-daily regimens compared to twice-daily therapy. The adherence advantage of once-daily treatment was apparent in treatment-naive individuals, as well as people switching therapy with detectable viraemia and also people who changed treatment with an undetectable viral load. The difference between these subgroups was significant ( $p = 0.02$ ).

Virologic outcomes did not differ significantly between once- and twice-daily regimens. The investigators believe there are several possible explanations for

this finding. These include the relatively small difference in adherence rates between once- and twice-daily regimens; the short period of follow-up in many studies; and the high levels of adherence support provided in clinical trials. 'For all these reasons,' write the investigators, 'the difference in virologic suppression that we found between once- and twice-daily ART regimens may be understated.' They conclude that once-daily treatment is associated with better adherence, and that higher pill burden is associated with poor virologic outcomes.

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Michael Carter

Adapted from [www.aidsmap.com](http://www.aidsmap.com)  
Published: 31 January 2014

### LOW CD4 COUNT DESPITE VIRAL SUPPRESSION IS ASSOCIATED WITH A BIG INCREASE IN MORTALITY RISK

A low CD4 cell count is associated with increased mortality risk, even if people are taking virologically effective HIV therapy, an international team of investigators report in the online edition of *Clinical Infectious Diseases*. People with incomplete CD4 count recovery – a count below 200 cells/mm<sup>3</sup> – despite three years of treatment with virologic suppression had a more than two-fold increase in their mortality risk compared to people with more robust immune reconstitution.

Factors related to incomplete CD4 cell recovery included older age, transmission via male heterosexual sex or injecting drug use, lower CD4 count at start of the suppressed period and longer time from initiation of antiretroviral therapy to start of the virally suppressed period. The authors argue their findings underline the importance of earlier HIV diagnosis and the prompt initiation of therapy, and urge that people with incomplete CD4 count recovery should be closely monitored for certain diseases, including hepatitis and non-HIV-related cancers.

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Michael Carter

Adapted from [www.aidsmap.com](http://www.aidsmap.com)  
Published: 14 February 2014

### REASONS FOR DELAYING ANTIRETROVIRAL THERAPY

A survey of HIV-positive people and their doctors in the European Union and Australia found that barriers to initiating antiretroviral therapy still exist but are different from those of the late 1990s. Researchers recruited 508 HIV-positive patients (84% men) with an average age of 37 years, and who had been diagnosed between one and four years ago. During the same period, 114 doctors were recruited, 60% of whom had at least 10 years of experience treating people with HIV.

The main reason that HIV-positive people gave for delaying therapy were: 'I rely on my body to tell me when to start'; the desire to delay starting therapy until symptoms occurred; and not wanting to be reminded about their HIV status. Overall, 50% of participants with a CD4 count less than 500 cells were not ready to start; and 30% of participants with a CD4+ cell count less than 500 cells were ambivalent about starting.

Major reasons by doctors for delaying the initiation of ART include that they perceived some of their patients to be suffering from a degree of depression, that there was active substance use and that patients did not understand the need to adhere to HIV medicines.

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

23–24

#### **Advancing the Agenda 2014: National Conference for Women with HIV**

Melbourne, Australia

<http://www.positivewomen.org.au/content/view/88/130>

### ● **April**

7–10

#### **National Gay Men's HIV Health Promotion Conference 2014**

Sydney, Australia

<http://www.afao.org.au/events/hiv-health-promotion-conference>

### ● **May**

21–23

#### **International Symposium on HIV and Emerging Infectious Diseases 2014 (ISHEID 2014)**

Marseille, France

<http://www.isheid.com>

### ● **June**

12–13

#### **10th International Workshop on HIV & Hepatitis Co-infection**

Paris, France

<http://www.virology-education.com>

### ● **July**

17

#### **2nd Annual Kirby Institute Symposium**

Sydney, Australia

<http://www.kirby.unsw.edu.au>

### ● **July (continued)**

17–19

#### **Our Story, Our Time, Our Future: 2014 International Indigenous Pre-conference on HIV & AIDS**

Sydney, Australia

<http://www.indigenoushivaid2014.com>

18–19

#### **6th International Workshop on HIV Pediatrics**

Melbourne, Australia

<http://www.virology-education.com>

18–19

#### **International HIV/Viral Hepatitis Co-Infection Satellite Meeting**

Melbourne, Australia

<http://www.etouches.com/ehome/index.php?eventid=78381&>

19–20

#### **Setting the Pace: Gay Men, MSM, and Transgender People in the Global AIDS Response (MSMGF AIDS 2014 Pre-conference)**

Melbourne, Australia

<http://www.msmsgf.org>

19–20

#### **Towards an HIV Cure Symposium**

Melbourne, Australia

<http://hivcure.aids2014.org>

20–25

#### **20th International AIDS Conference (AIDS 2014)**

Melbourne, Australia

<http://www.aids2014.org>

### ● **September**

17–19

#### **Viral Hepatitis 2014**

Alice Springs, Australia

<http://www.hepatitis.org.au>

# ENDING HIV

Everything has changed. Advances in HIV treatment offer improved health benefits and the potential to dramatically reduce the risk of HIV transmission among gay men by 2020 if we:

$$\left[ \begin{array}{c} \text{TEST} \\ \text{MORE} \end{array} \right] + \left[ \begin{array}{c} \text{TREAT} \\ \text{EARLY} \end{array} \right] + \left[ \begin{array}{c} \text{STAY} \\ \text{SAFE} \end{array} \right] = \left[ \begin{array}{c} \text{ENDING} \\ \text{HIV} \end{array} \right]$$

Get tested at least twice a year. To decrease undiagnosed infections, to increase access to treatments, more of us need to know our HIV status earlier.

Poz guys - advances in HIV treatment offer improved health benefits and the potential to dramatically reduce the risk of passing on HIV.

By testing more often, by treating earlier and by continuing to stay safe, we can drive new infections among gay men down by 80% by 2020.



**ENDINGHIV.ORG.AU**