HIV
AUSTRALIA

HIV AND THE SOCIAL MEDIA REVOLUTION

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.

AFAO Board
President Ian Rankin **Vice President** Willie Rowe
Secretary Nic Parkhill **Treasurer** Andrew Burry
Ordinary Member Chris Lemoh **Staff Representative** Finn O'Keefe
AIVL Jenny Kelsall **Anwernekenhe National Alliance** Michael Costello
NAPWA Robert Mitchell **Scarlet Alliance** Kane Matthews

In this edition of *HIV Australia*, authors reflect on the impact of social media and other digital technologies on responses to HIV. Contributors discuss how health promotion and health management systems are adapting to changing digital environments and the increasing socialisation of the web.

HIV Australia online includes additional content not published in the printed edition. Read more of *HIV Australia* at www.afao.org.au

We want to hear what you think about *HIV Australia*. Please send your feedback to the Editor, editor@afao.org.au or write to us at:
HIV Australia
C/– AFAO, PO Box 51, Newtown NSW 2042 Australia

NEWS

AUSTRALIAN NEWS

Urgent resolution to salvage Queensland's HIV partnership response

On 30 May, delegates at the AFAO National Gay Men's Health Promotion Conference in Sydney passed an urgent resolution calling on Queensland Health to review its decision to defund Healthy Communities, the key HIV community sector partner in Queensland.

The resolution was made in response to Health Minister Lawrence Springborg's announcement, made by media release on 20 May, of plans to redirect $2.6 million worth of funds away from Healthy Communities to an as yet unformed Ministerial Advisory Committee on HIV/AIDS.

Healthy Communities say that the Minister's assertion that current Queensland HIV programs are failing is unfair, noting that the organisation is specifically funded for HIV prevention work targeting gay men and men who have sex with men (MSM), and HIV rates have decreased among these communities as a proportion of people diagnosed with HIV in Queensland over the past 10 years.

Australian health groups and national bodies, including the Australian Federation of AIDS Organisations, the LGBTI Health Alliance, the Public Health Association of Australia and the Australasian Society of HIV Medicine, have all made statements supporting the work of Healthy Communities, and urging the government to work in partnership with the organisation rather than pre-emptively defunding it.

Healthy Communities have sought urgent meetings with the Health Minister and Premier to discuss the decision.

Review recommends changes to blood donation rules

An independent Review of Blood Donor Deferrals Relating to Sexual Activity has recommended halving the 12-month deferral period between sexual activity and blood donation for men who have sex with men (MSM). Currently, the Red Cross Blood Service defers donations by potential donors – including MSM and sex workers – who disclose 'risk behaviour' within the past twelve months, either temporarily or indefinitely.

The review also recommended reducing the deferral period for sex workers, a group which is at lower risk of acquiring and transmitting sexually transmitted infections (STIs) than other heterosexuals, but said further research in to non-brothel based sex workers is needed to help inform future deferral policy.

The committee recommended that the Blood Service consider the results of a compliance study before implementing the recommendation to reduce the deferral period. This study, investigating whether reducing the deferral period will threaten the safety of the blood supply, will be conducted in collaboration with the Kirby Institute.

Starting the treatments conversation

A new campaign from NAPWA urges people living with HIV talk to their doctors about the benefits of HIV treatment for themselves and their partners.

The campaign, which features print media ads, billboard posters and a website, was launched by media personality and former Chairwoman of the National Advisory Committee on AIDS (NACAIDS) Ita Buttrose on 4 May in Sydney.

Speaking at the launch, NAPWA President Robert Mitchell said that 'many people with HIV are still unaware of recent treatment improvements, new information about living with HIV long term, and the added benefit that being on treatment can have in reducing the risk of HIV transmission'.

NAPWA's campaign is the first of its kind in Australia to use mainstream media and public advertising sites to promote HIV treatment awareness.

For further information, visit the campaign website at http://hiv.napwa.org.au.

INTERNATIONAL NEWS

$1.6 billion injection for the Global Fund

In a turn-around from last year's funding freeze, The Global Fund to Fight AIDS, Tuberculosis and Malaria estimates that more than $1.6 billion in additional funding will be available for the 2012–14 period.

This new estimate is a result of strategic decisions by the Global Fund's Board, including a restructuring of the Fund and changes to the management of grants. The Fund has also attracted funds from new donors, and an increased commitment from some of the current donors. Cash has also been freed up because some former recipients of grants – notably China – have offered to support projects in their own country.

Michel Sidibé, Executive Director of UNAIDS, welcomed the announcement. 'This ushers in a new era for the Global Fund and I am pleased to see that it is opening the door to new partnerships,' he said.

FDA decision on the approval of *Truvada* for PrEP delayed three months

The US Food and Drug Administration (FDA) has extended its review of

Gilead Sciences' approval application for *Truvada* (tenofovir plus emtricitabine) to be marketed for pre-exposure prophylaxis (PrEP) use. A decision was originally expected in mid-June but this has since been delayed until 14 September to allow the FDA time to consider a revised risk mitigation strategy submitted by Gilead on 4 June.

'The FDA has indicated that this extension relates to the agency's standard administrative procedures for reviewing Gilead's proposed Risk Evaluation and Mitigation Strategy (REMS) for *Truvada* as PrEP,' Gilead's Gregg Alton said in a statement regarding the delayed decision.

AFAO Executive Officer, Rob Lake, said that US endorsement of *Truvada* for HIV prevention would be an historic step forward in the fight against HIV/AIDS worldwide, and urged the Australian Therapeutic Goods Administration to take heed of the recommendation. 'We urge immediate local research to identify the best options for the effective use of *Truvada* in Australia for HIV-negative people. We need to be looking for licensing to progress and trials in an Australian context to get underway,' Mr Lake said.

Resolution on HIV testing access in Australia

In May, delegates at the AFAO National Gay Men's Health Promotion Conference in Sydney passed a resolution on HIV testing access, recommending barriers to testing in Australia be addressed as a matter of urgency.

The resolution noted that the approval of home testing has contributed to addressing HIV transmission rates in other developed countries, and called on the Australian HIV partnership to work towards making rapid HIV testing routinely available in Australia.

The resolution follows a unanimous vote made by a US FDA advisory committee, also in May, recommending

approval of OraQuick, an over-the-counter HIV test, for home use.

OraQuick has been used by health care practitioners in the US since 2004, but has not been approved for home use previously because the test falls short of the FDA's recommended 95% threshold for accuracy. The FDA estimates that if approved, the test would miss about 3,800 HIV-positive people each year, however, it could also greatly increase the number of diagnoses in people who were not aware they had HIV.

WHO's new plan on antiretroviral treatment as prevention

On 8 June, The World Health Organization (WHO) released a Programmatic Update on Antiretroviral Treatment for Prevention of HIV and TB, which sets out the organisation's plans to ensure treatment as prevention (TASP) as a key element of combination HIV prevention and a major part of the solution to ending the HIV epidemic.

The report follows revised US antiretroviral treatment guidelines issued by the US in April that recommend all people living with HIV consider commencing treatment, regardless of CD4 cell count. The WHO report gives a working definition of treatment as prevention as including: commencing ART irrespective of CD4+ cell count for the prevention of HIV and TB and the provision of ART to people living with HIV who are:

- severely immune-compromised with AIDS and/or have a CD4+ count ≤350 cells/mm³
- those with higher CD4+ cell counts >350 cells/mm³.

At a recent summit in London coinciding with the release of the report, the head of the WHO's HIV department, Dr Gottfried Hirnschall, stated that the number of people eligible for antiretroviral treatment will grow by around six million as a result of recent WHO recommendations.

WHO has begun a comprehensive revision of all guidelines related to use

of antiretrovirals, including guidance on TASP, planned for release in 2013.

ASIA-PACIFIC NEWS

Action to safeguard treatment access against free trade agreements

A three-day regional Consultation was held in Bangkok in May to discuss the potential impact of free trade agreements on HIV treatment access throughout Asia. Representatives from the nine countries at the meeting agreed that urgent action is needed to ensure that access to antiretroviral medication is not impeded by trade agreements.

Countries are facing mounting challenges to produce or procure affordable HIV treatment, including cutbacks in HIV funding and a proliferation of increasingly restrictive intellectual property measures in free trade agreements. During the Consultation, delegates took steps to accelerate actions within their respective countries to try to address the situation.

A key factor in determining the sustainability of treatment programs throughout Asia rests with India's pharmaceutical industry. India produces over 85 percent of all first generation antiretroviral drugs used to treat people living with HIV in low and middle income countries. India is currently negotiating a free trade agreement with the European Union (EU), which it is hoped will contain pro-development provisions that would enable access to treatment in India and other countries in Asia and the Pacific.

A UNAIDS/UNDP joint issues brief, the *Potential Impact of Free Trade Agreements on Public Health*, was also launched to coincide with the regional Consultation. 'The sustainable future of HIV treatment programs in Asia is of serious concern,' said Steven J. Kraus, Director, UNAIDS Asia and the Pacific. 'Countries must use all the means at their disposal, including the TRIPS flexibilities, to increase treatment levels and to reach people most in need.'

TREATMENT AS PREVENTION: *FESTINA LENTE* (HASTEN SLOWLY)

By Sean Slavin

Two years ago I wrote a chapter for an AFAO monograph on treatment as prevention that welcomed the news that antiretroviral treatments (ARVs) have a preventative effect on transmission but noted the paradoxical nature of the technology in the context of a set of changing relationships to risk in the sexual lives of gay men.[1] I argued that at the heart of this paradox lies the distinction between individuals and populations and the fact that interventions designed to have a population benefit might not be sufficiently effective for individual use.

Much of the discussion in the past two years about biomedical prevention technologies in Australia has, implicitly if not explicitly, occurred in the context of population benefits and risks. I maintain that the preventative effects of HIV treatment should be warmly welcomed, however there is a need for ongoing consideration of the meaning of these technologies for individuals and communities.

No 'one size fits all'

In thinking about whether to use treatment as prevention as an individual strategy, a person might ask: 'Will it work to prevent me passing on HIV to my partners?' The answer to this will be a cautious 'yes' circled with a number of caveats, the most significant for gay men being 'we only have good evidence of this in the context of heterosexual sex.' If it's a gay person asking, then the honest answer must currently be something like: 'It will work to reduce the risk of transmission. To what extent, we don't know and its effectiveness is probably influenced by a range of other factors including the presence of STIs.'

> If the question about whether treatment as prevention is asked in relation to populations there are a different set of theoretical answers that depend on the scale of HIV testing and the uptake of treatments across the population.

So given that the risk of transmission in the second case is located somewhere on a sliding scale – but the outcome, HIV infection, is something that is absolute (you either have or you don't) – if you absolutely want to prevent HIV transmission then you would be well-advised not to rely solely on this approach. If you are prepared to entertain the idea that transmission might occur, then this approach may help to make this less likely. Entertaining the idea that transmission might occur would hopefully be a decision made after careful consideration of the long-term ramifications.

If the question about whether treatment as prevention is asked in relation to populations there are a different set of theoretical answers that depend on the scale of HIV testing and the uptake of treatments across the population. Given that incident HIV infections in Australia continue to occur at the same or increased rates as in the past it is safe to assume that we have not yet achieved high enough rates of testing or treating. But how much is enough to have an effect on HIV incidence?

According to modelling done by David Wilson at the Kirby Institute for infection and immunity in society, in order to achieve a 50% reduction in new infections over two years we would need to increase testing four-fold and increase the proportion of people on treatment from 70% to 90%. According to the proponents of the test and treat idea, if you achieve universal coverage of both, then HIV can be eradicated in a population.[2] Now, this is the sort of talk that gets blood rushing to the heads of those in public health, reminding them of the golden age of mass vaccination. But antiretroviral therapy is patently not a vaccine. Even the simplest drug combinations require daily dosing and better than 95% adherence, for a lifetime.

In whose interest?

I think we conflate individual and population discussions of HIV treatment at our peril. For example, a public health approach may say that

treatment should be started as soon as possible after diagnosis in order to reduce the risk of onward transmission, regardless of whether treatment is clinically indicated. It is argued that viral load is often extremely elevated during acute infection (although only a small proportion of diagnoses are made during this stage) and there is a high risk of secondary infection. Reducing viral load would reduce this risk. There are several serious problems with this proposal.[3]

First, viral load does not drop instantly once treatments are started. In most individuals it takes many weeks (if not several months) to achieve an undetectable viral load. So while there may be a theoretical population benefit in treating at this point, individuals would be ill-advised to rely on this approach to prevent transmission.

Second, there is currently no evidence to support an individual health benefit for starting treatments before CD4 cells fall below 500/µl.[4] Many clinicians are uncomfortable making treatment recommendations on grounds other than individual patient need.

Third, this approach implicitly diminishes the potential benefits of less invasive interventions such as education and counselling. By fully discussing the increased risks of onward transmission with those diagnosed during the acute phase of infection, behaviour change that includes strict adherence to condoms or abstinence for a period becomes available.

Fourth, this proposition about the higher levels of infectivity during primary infection is based on limited evidence. On the face of it, it seems plausible, but do we base a major prevention intervention on an idea that seems plausible?[5]

The decision to start treatment is almost always a weighty one, which should not be rushed if the best possible long-term outcome is to be achieved. Receiving an HIV diagnosis is still difficult and traumatic for most people and for many there is no great urgency to start treatment immediately. Why conflate

the two issues and risk exacerbating the trauma of diagnosis and creating a negative impression of treatment?

Complex decisions and subtle pressures

While I don't think there's any real risk of coercive treatment in Australia, people living with HIV nonetheless endure subtle pressure that places them in a position of greater responsibility for prevention. An example in the United States was the campaign 'HIV stops with me' (hivstopswithme.org) which was underpinned by the Center for Disease Control's position on positive prevention that emphasises disclosure and personal responsibility.[6] Using treatment to affect the spread of HIV would likely involve aspects of this approach.

Notwithstanding some of the reservations I have about the effectiveness of treatment as prevention, I do wish to acknowledge that, for many people living with HIV, an undetectable viral load allows them to feel less infectious and less anxious about transmitting the virus to sexual partners. This is obviously a good thing, if it's a second order outcome of a decision to treat. It's obviously problematic if the person with HIV feels obligated to treat.

We should also be cautious in ascribing this anxiety to all people living with HIV, or assuming that taking treatments will necessarily

alleviate the anxiety. In research conducted by NAPWA (National Association of People Living With HIV/AIDS) and the NCHSR (National Centre in HIV Social Research) that is currently being analysed about experiences of HIV stigma, we have found HIV -positive people expressing internalised stigma in forms such as 'feeling dirty' or 'feeling infectious'. However, when we look at whether these feelings occur more often among those not on treatment, there appears to be no correlation. Likewise, for many HIV-positive people, adherence to safe sex is adequate to reduce their anxieties about transmission.

Another issue raised by the idea of treatment as prevention is how we understand and talk to people with HIV who do not take treatments. It is estimated that approximately 30% of people living with HIV do not take ARVs and we currently understand little about their thinking or motivations.

While we await data on this group, I can only bring to mind friends who have decided for the moment not to treat. These people have not made these decisions out of ignorance. They are well-informed about both HIV disease and treatments and don't hold any radical unscientific views along the lines that HIV doesn't cause AIDS.

While I don't think there's any real risk of coercive treatment in Australia, people living with HIV nonetheless endure subtle pressure that places them in a position of greater responsibility for prevention.

In fact they hold very normal beliefs about staying well by maintaining a healthy lifestyle, as well as reservations about putting serious drugs into their bodies unless they are absolutely warranted and fears that regular pill taking will have a significant impact on their lifestyle. These people monitor their CD4 and have ongoing relationships with a doctor.

People like this are acutely aware of the complexity of treatment decisions and it would be inaccurate to regard them as suffering a deficit of knowledge or holding irrational beliefs. In the end it surely must be the right of any person with HIV to make a decision in relation to treatments that we may disagree with. A related issue is the question of people who do take treatment but cannot achieve an undetectable viral load (about 12%).[7] Does this represent a failure of treatment as prevention? What should we be advising these people about the transmission risks of having a detectable viral load?

In the discussions occurring across the sector about combination prevention or more optimistically the 'prevention revolution', we have quickly become accustomed to the mantra that biomedical technologies are options to be used in addition to condoms. But how realistic is this for individuals? Why would an HIV-negative gay man use PrEP

(pre-exposure prophylaxis) and condoms? If treatment as prevention really works, why would serodiscordant couples continue to use condoms? The reality is that most people will identify these things as alternatives. Some will gladly abandon condoms while others may be cautious about embracing drug-based technologies that are arguably much more interventionist. It remains to be seen what the social or community effects will be when some gay men choose to stick with condoms while others opt for different technologies. Given that stigma still exists around HIV in sexual contexts, will these technologies make this better or worse? Will HIV-positive people who are not on treatments become sexual pariahs?

Conclusion

I reiterate that realising HIV treatments have preventative effects has been overwhelmingly positive and this development should be welcomed. However, when scientists at the International AIDS Society Conference in Rome last year made the astounding claim that 'treatment is prevention' this should sound some warnings for us in the community sector. We should remember that prevention is something we've been doing very effectively for 30 years within gay communities. While we have spent quite a bit of energy in the past decade trying to understand what's wrong with condoms as a prevention tool, we perhaps also need

to spend energy understanding what's right about them for a significant proportion of gay men.

Further, I think whenever science declares it has found the silver bullet we should maintain our scepticism, openness to dissenting views (including 'non-scientific' community views) and confidence in our experience of knowing what already works. Prevention has not become simpler because of scientific discoveries in recent years, risk has become infinitely more complex. It is more important than ever that community based organisations remain central to interpreting these developments and communicating with real life individuals in the community about how to prevent HIV. Quite a different conversation to the ones we have with scientists and funders about reducing population level risk.

References

1   Murphy, D. [ed.]. (2010). Trick or Treat? Antiretroviral therapy as HIV prevention. *AFAO Biomedical Prevention Monograph No. 1*. Australian Federation of AIDS Organisations, Sydney. Retrieved from: http://www.afao.org.au/__data/assets/pdf_file/0015/4524/trick_or_treat.pdf

2   Granich, R., Gilks, C., Dye, C., De Cock, K., Williams, B. (2009). Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. *Lancet, 373*, 48–57.

3   Fidler, S., Fox, J., Porter, K., Weber, J. (2008). Primary HIV infection: to treat or not to treat? *Curr Opin Infect Dis, 21*, 4–10.

4   Bell, S., Little, S., Rosenberg, E. (2010). Clinical management of acute HIV infection: best practice remains unknown. *J Infect Dis, 202*, Suppl 2, S278–S288.

5   Myron, S., Cohen, M., Shaw, G., et. al. (2011). Acute HIV-1 Infection. *N Engl J Med, 364*, 1943–1954.

6   Centers for Disease Control and Prevention. (2003). Advancing HIV prevention: new strategies for a changing epidemic. *MMWR, 52*(15), 329–32.

7   The Kirby Institute. (2011). *The Australian HIV Observational Database Annual Report. Volume 11, Number 1*. The Kirby Institute, University of New South Wales, Sydney. Retrieved from: http://www.med.unsw.edu.au/NCHECRweb.nsf/resources/AHOD_5/$file/AHOD_Annual_Report_2011_FINAL.pdf

Sean Slavin is Assistant Director and Manager of Research Programs at the National Association of People Living with HIV/AIDS (NAPWA).

> … realising HIV treatments have preventative effects has been overwhelmingly positive and this development should be welcomed. However, when scientists at the International AIDS Society Conference in Rome last year made the astounding claim that 'treatment is prevention' this should sound some warnings for us in the community sector.

HOW SOCIAL MEDIA STRATEGY CAN HELP PLAN, RUN AND EVALUATE HEALTH PROMOTION

By Lyndal Cairns

This article details the way social media is used at Healthy Communities in Queensland and the importance of strategy in reaching our goals of HIV prevention.

Getting the strategy right

We have found that social media policy, strategy and planning are vital to the success of our projects. Long before the condom reinforcement campaign Rip and Roll was relaunched in late May 2011, Healthy Communities had a plan for social media and had established a Facebook page[1], Twitter account[2] and content strategy[3]. This meant that when the campaign's poster of a male couple holding a condom was pulled from bus shelters, we were well placed to capitalise on the groundswell of public support through Facebook and Twitter.

An event was set up immediately after the ad was removed and it gained 1,000 'attendees' (supporters) in four hours, 35,000 supporters in a day and 91,000 to date.[4] Mainstream and international media coverage[5] followed and the Rip and Roll campaign poster was soon reinstated. Because we had done the groundwork and set up accounts beforehand, we were able to capitalise on the support immediately and transfer it into permanent engagement with our health workers through the Facebook and Twitter accounts. In addition, the increased interest in the campaign and in Healthy Communities as an organisation has increased discussion about HIV and sexually transmitted infections (STIs) in Queensland.

Evaluation through social media

A survey of the target population conducted after the Rip and Roll campaign showed the worth of the campaign and demonstrated its message was being received.[6] Some 93.7% of respondents recognised the campaign was about condom reinforcement; and 80% reported that condom use was very important to them. In addition, nearly 70% said HIV and STI prevention was a goal for the campaign and they also said it was very important to them (HIV prevention 95.3%; STI prevention 90.6%).

Lessons learnt

The sheer speed of the social media response was challenging for Healthy Communities as we tried to manage traditional and new media demands, and capitalise on the small window of opportunity for our messages that big media coverage afforded us.[7] We tried to focus on updates and what our community really needed to know and put the best of the rest in links.

It also taught us the importance of partnerships with organisations and people who have large social media followings (influencers), and getting access and administrative rights to growing communities online.

Learning from our community

Healthy Communities workers have an increased capacity to tap into the knowledge held in the community. This is especially true of the Sexually Adventurous Men project (SAMs), which was set up in response to the over-representation in HIV notifications of men engaged in esoteric sex. Research was conducted with Queensland men through social media sites serving SAMs[8] and at parties and beats. The research showed a skills deficit in the community and a need for appropriate peer education. Based on the research, Healthy Community's SAM project worker Deeje Hancock created a secret space for like-minded men to discuss and educate each other about esoteric sex best practice and risk reduction. The intervention has been extremely successful, with scene elders identified and supported to give good-quality information to at-risk people new to the scene.[9]

Information from the SAMs community has also informed the SAMs section of the men.org.au website, which will be launched later this year.

… the increased interest in the campaign and in Healthy Communities as an organisation has increased discussion about HIV and sexually transmitted infections (STIs) in Queensland.

Organisational change as an adjunct

Our social media successes are also changing the way we work day-to-day. The ease and strength of our social media networks – especially Facebook – means staff can promote their activities more effectively. In crafting a social media strategy, health workers must consider their objectives and create targets, working more ahead of time and in a more coordinated way than previously. And the ease with which social media offers analytics means they evaluate their projects more effectively.

Identifying impediments to open communication

A survey of Healthy Communities staff's social media use, skills and attitudes, conducted in March, found health workers relied heavily on networks to promote events, build community and talk about sexual health.[10]

Half the sexual health program staff reported that gay hookup phone app Grindr was very useful.

However, only 37% said they were very successful in talking about health online. Delving into why, a full two thirds said they struggled to find at-risk people and engage them appropriately online; and a further quarter said they

were afraid of being misunderstood. This honest response from staff means we are able to identify skills deficits and target training. As a result, Healthy Communities is developing a digital flowchart of sexual health questions which will guide health workers and give them confidence.

Keeping track of our work

At Healthy Communities, plans are written for every social media campaign. These include the rationale for our work, the tactics we plan to use, suggested content and an evaluation framework so we know whether we are meeting our targets.[11]

The wealth of data available in social networks allows health workers to evaluate sexual health conversation better. Instead of stopping to think after a phone or live conversation and evaluating whether the client has understood them, it is often set out in front of them in the conversation. They can see their client's response, and for the most part have continued contact with them.

Going forward, Healthy Communities plans to further diversify its social media networks (including a niche community for clinicians) and has built social elements into its websites, which will be relaunched in the middle of the year. Staff will be trained in online

health promotion, social media analytics and developing 'viral', or shareable, content – especially video.

References

1   Rip and Roll Facebook page. Retrieved from: http://www.facebook.com/rip.roll

2   Rip and Roll Twitter account @rip_n_roll. Retrieved from: http://www.twitter.com/rip_n_roll

3   Lewis, C., Junior (2011). *Rip and Roll phase II campaign plan*. Healthy Communities, Queensland.

4   James, M. (2011). Homophobia – NOT HERE – Adshel Caves to Homophobic Pressure Facebook event. http://www.facebook.com/events/123532344395752/

5   The Rip and Roll story YouTube playlist. Retrieved from: http://www.youtube.com/watch?v=Dohp7rN_w10&feature=share&list=PL1773D9A08DB4309B

6   Cairns, L. (2011, 2012). *Rip and Roll Engagement Survey*. Healthy Communities, Queensland.

7   Norton, G., Cairns, L. (2011). *rip&rolled – How Social Media Beat Homophobia and Solidified a Community*. Retrieved from: http://qahc.org.au/files/shared/rip_roll_afao_with_links_0.pdf

8   Hancock, D. (2011). *Sexually Adventurous Men Behaviours Skills and Knowledge in Queensland*.

9   Cairns, L. Hancock, D. (2012). *Sexually Adventurous Men Project Secret Group Evaluation Framework*.

10 Cairns, L. (2012). *Social Media Skills Assessment Survey*, Sexual Health Team.

11 Healthy Communities Social Media Policy.

Lyndal Cairns is social media coordinator for Healthy Communities.

Help save Healthy Communities

Soon after Healthy Communities submitted this article, the Queensland Government announced its intention to completely defund the organisation, redirecting funds to an as yet unformed new Ministerial advisory committee. This decision will effectively terminate all HIV prevention programs the organisation operates across Queensland.

Healthy Communities has developed a series of strategies, including the use of social media, to raise awareness about the decision. A Facebook event was set up by Lyndal Cairns immediately following the announcement, and two public protests have already been staged, with more action to follow.

What you can do:

1. Contact the Queensland Health Minister (email: Health@ministerial.qld.gov.au) and Premier (thepremier@premiers.qld.gov.au) and call for Healthy Community's funding to be reinstated

2. Submit a testimonial about what Healthy Communities means to you by video or email LCairns@qahc.org.au - these will show the Queensland Government how much support we have in the community

3. Donate to the campaign fighting fund – www.healthycommunities.org.au/donation

4. Join the 'Save Healthy Communities' campaign on Facebook (http://www.facebook.com/events/312518542160186) or use the hashtag #saveQAHC on Twitter

5. Further information and background at www.healthycommunities.org.au/saveQAHC

Resolution on the breakdown of the Queensland HIV Partnership Response

At the AFAO National Gay Men's HIV Health Promotion Conference, held in Sydney 28–30 May, a resolution was unanimously passed by conference delegates regarding the Queensland government's intention to strip LGBT health organisation Healthy Communities of funding for all HIV prevention and gay men's health programs. Read the full statement below:

The Conference notes with alarm the Queensland Government's announcement on 20 May 2012 to remove funding from Healthy Communities for its HIV prevention work with gay men and its other health promotion programs.

The decision was made without consultation and will seriously disrupt the provision of services to prevent HIV transmission in one of Australia's most populous states. The Queensland HIV epidemic has unique characteristics, but, as is the case all around the country, the majority of the epidemic is directly affecting gay men. To stop working programs, to sack employed staff and destroy community networks will set back HIV prevention efforts both in Queensland and across Australia.

The conference supports the call by Healthy Communities for Minister Springborg to work with them and other members of the HIV partnership in Queensland to review the approach, and consider the impact of changes in the patterns of sexual transmission of HIV in Queensland and make decisions about funding on the basis of the review, rather than pre-emptively defunding Healthy Communities.

It is internationally recognised that HIV prevention has always worked best in a partnership approach between affected communities, government, clinicians and researchers. The Conference calls on the Queensland Government to return to working in partnership with all sections of the HIV response, and to recognise that those affected by HIV are best placed to determine their health promotion needs.

The conference affirms its support of the HIV prevention work of Healthy Communities and their success over more than 20 years in limiting the transmission of HIV among gay men in Queensland and providing effective HIV education, and contributing to the Australian HV response.

Voices from the blogosphere

Following the Queensland Government announcement, a number of concerned community members and organisations have published their thoughts about Queensland Health funding announcements. Below are some examples:

■ **Sounding the alarm over cutbacks to Qld organisation for lesbian, gay, bisexual and transgender health** Daniel Reeders, via Croaky, May 21 2012: http://bit.ly/soundingthealarm

■ **The great leap backwards** Paul, via Buggery.org, May 20 2012 : http://bit.ly/leapbackwards

■ **North of the border** Sail, via View from the quarterdeck, May 21 20112: http://bit.ly/sailnorth

■ **Who Should Be Educated In The Fight Against HIV?** George Forgan-Smith, via The Healthy Bear, May 24, 2012: http://bit.ly/politicalprice

AFAO has also collated a range of current information about the funding decision on its blog:
■ **Healthy Communities (QAHC) to be defunded** AFAO Talks blog: http://bit.ly/HCdefunded

On 30 May, around 2000 people Marched to Parliament House in Queensland at an emergency rally, entitled 'Equal Love Brisbane', protesting against the defunding of Healthy Communities (QAHC) and amendments to legislation preventing state-sanctioned ceremonies for civil unions.
Photo: Charlyn Cameron

FACEBOOK, GAY MEN AND HIV PREVENTION: THE NEW *MÉNAGE À TROIS*?

Yves Calmette looks at the emergent power of Facebook to reach and (re)engage with gay men.

Social media is currently the most popular online activity worldwide; social networking sites now reach 82% of the online population, representing 1.2 billion users around the world.[1]

The popularity of social media is even more evident when examining the amount of time people spend engaging with it. Research from ComScore indicates that social media use has more than tripled in the last few years, with users now devoting nearly one in every five minutes of the time they spend online with social networking activities.[2] This is a huge increase from March 2007 when social networking accounted for only 6% of the total time spent online; over the past year alone, the total time individuals spent using social media grew by 35%.[3]

This rapid growth of social media's popularity has been further accelerated by the growth in mobile social media use, driven largely by the increasing popularity of smartphones. Australia has the second highest smartphone penetration by population density in the world.[4] In 2011, the percentage of Australians who owned a smartphone grew from 37 to 50% and this figure is projected to increase further in 2013; little wonder that Australia ranks as the #1 online population using social media.[5]

Nevertheless, organisational uptake of social media has been relatively slow. For example, according to a 2010 study conducted by the Harvard Business Review in the US, only 12% of companies and organisations surveyed indicated that they were effective users of social media and just 7% said they were able to integrate social media into their marketing activities.[6]

At the same time, research clearly demonstrates that much of gay men's connection and engagement is via online environments. 30 years into the HIV epidemic, engaging gay men with health promotion messages through traditional channels is becoming extremely challenging. They pay less and less attention to these messages – and a large majority no longer engages regularly with gay print media.[7,8] Health promoters are therefore urged to adapt accordingly and quickly master all the possibilities the digital world and social media have to offer.

Facebook's viral reach

To fully understand the state of social media today, we must appreciate the immense influence Facebook has on the entire social media category; it is the largest social media player by any metric and the third largest website in the world, following only Google and Microsoft.[9] In October 2011, Facebook was accessed by more than the half of the world's internet users, accounting for up to 90% of time people spent on social media sites and one in every seven minutes spent online overall.[10] Research shows that gay men have enthusiastically embraced Facebook, with approximately 75% of gay men in the US reporting that they had a Facebook profile in 2010.[11] Two surveys confirmed that 75% of Australian gay men use Facebook every day while only 21–28% reported reading the weekly gay press every week.[12,13]

'Fans' and friends of fans

Facebook's reach is much greater than the number of 'fans' of a particular page; the site enables innovative ways of sharing amongst friends that accelerates the viral reach of content. Many organisations tend to focus only on the number of 'fans' they attract (i.e. people who have directly 'liked' their Facebook page); however, the friends of these fans constitute a second potential audience. This group is much larger than a pages' primary fan base (34 times on average, for the top 100 brands on Facebook[14]) and receives social media content via their friends.

In addition, the potential level of interest friends of fans have in the content might be as high as the fans themselves. Although they might not

> Research shows that gay men have enthusiastically embraced Facebook, with approximately 75% of gay men in the US reporting that they had a Facebook profile in 2010. Two surveys confirmed that 75% of Australian gay men use Facebook every day while only 21–28% reported reading the weekly gay press every week.

be willing to explicitly 'like' a page themselves, they are still likely to be interested in what their friends 'like' or engage with. Therefore, an organisation working on acquiring and engaging fans can benefit from a significant secondary effect that provides additional exposure often surpassing the reach among fans.

Case study: The Big Picture campaign

For its The Big Picture social marketing campaign, ACON sourced the specific benefits Facebook offers for updating gay men's knowledge about the current state of the HIV epidemic in New South Wales, Australia.

ACON set up a dedicated Facebook page linked to a website containing the most up-to-date epidemiological and behavioural research into HIV and gay men in Australia.

Daily updates were posted under four topic headings: HIV (notification/risk behaviour) rates; Who is most at risk; Living with HIV; and Stepping up to drive infections down. The relevance and impact of posts was enhanced via an optimised online experience mix of open and poll questions, graphs, text-only posts, targeted ads and sponsored stories. ACON monitored social media activity in order to maintain an authentic 'Facebook grade' responsiveness to fan feedback.

A Facebook advertising campaign was also created to direct people to the Facebook page and to increase the number of fans. Fourteen different ads were developed, using different design, copy, and targeting techniques. These were shown over 8 million times and were directly attributed to the recruitment of up to 75% of new fans at a very low cost: $2,500. Interestingly, targeting men according to their interests related to gay clichés such as 'fans of Lady Gaga' or 'George Michael' proved to be more effective and sustainable than targeting men who specified in their profiles that they were, 'interested in men'. Ad copy that included the words 'gay' and 'HIV' were

Two examples of Facebook polls and open questions to optimise gay men's online experience and engagement with The Big Picture.

also more successful. And – surprise, surprise! – designs featuring photos of men also generated more clicks.

After eight weeks the Facebook page had gained more than 1,500 fans, offering viral onflow to a potential 535,000 friends. Every week, the page was seen between 50,000 and 100,000 times by fans and friends of fans on Facebook, extending target demographic impact potential far beyond traditional campaign engagement parameters.

We know that Facebook is particularly effective in reaching younger demographics. Research shows that men in the 35–54 age group spend half the amount of time on social media than the 20–24 age group.[15] However,

continued overleaf

people aged 55 and older are in fact the fastest growing group of social media users worldwide, exceeding 90% of users in some regions.[16] User engagement with The Big Picture campaign also indicates that Facebook is not only for young people: 30% of our fans were under 24, while 37% were in the 25–44 age group and 13% were over 45. It is interesting to note that for the first two weeks, 50% of our fans were under 25 but the targeting techniques we used ultimately also allowed us to reach older men.

Facebook also proved to be crucial in expanding the campaign reach and profile in the online space and was a primary driver of traffic to the website. The website attracted three times more traffic than previous campaigns with similar budgets and themes, but no activities on Facebook.

Interestingly, the level of interaction between the Facebook page and the fans was relatively limited. An average of 100 to 200 people 'talked' about the posts on a single week: they mostly 'liked' them and a few shared them or posted a comment, with a maximum of 2,300 people participating in or observing these interactions. 60% of people were exposed to the messages up to three times.

Barriers to interaction

It's not clear what the main barriers to interaction were but research on other Facebook campaigns suggests that:
- Facebook users are typically more engaged by content that relates to *them* and with which they can personally identify, as opposed to factual content (such as the Big Picture campaign).
- Facebook users also preference the simple and clear over the unfamiliar, lengthy and complex.

The external campaign qualitative evaluation[17] gives very valuable insights about the relatively low level of interaction:

- Many gay men – in particular older men – have concerns about Facebook privacy and security.
- Those who aren't openly gay don't want to be outed on Facebook.
- Others, even if they are totally comfortable with their sexuality, aren't entirely open to talking about HIV-related topics in a public space such as Facebook. They don't want their work colleagues, potential recruiters or families, to make assumptions about their sexuality or their HIV status.
- Many men will never consider adding to the conversation, preferring to read posts rather than contributing their own.

Conclusion

As social media continues to redefine the digital media landscape, health promoters have an ever increasing range of prevention message dissemination options.

The Big Picture experience demonstrates the power of the largely untapped prevention message reach potential within the Facebook Fans/ Friends viral flow. Creative use of rapidly evolving online communication methodologies offers as yet largely unexplored potential for engaging, listening and responding to online priority populations at risk of HIV.

Facebook is an invaluable tool for reaching mass audiences at low cost and offers a much more engaging next generation alternative to gay print media, which – like print media everywhere – is facing declining readership and relevance.

The great conundrum is that while Facebook is particularly effective in driving traffic to gay men's health promotion websites, it can't make gay men more interested in – or engaged with – the information they find on arrival. If we find the key to that, we could take the power of Facebook to the next level and make it one of the most effective (re)engagement options for gay men.

References

1 ComScore. (2011A). *It's a Social World: Top 10 Need-to-Knows About Social Networking and Where It's Headed*. Retrieved from: www.comscore.com/it_is_a_social_world

2 ibid.

3 ibid.

4 IPSOS/Google research quoted by Nett.com.au (2011). Australia has second highest global smartphone usage, study shows. Retrieved from: http://nett.com.au/news/australia-has-second-highest-global-smartphone-penetration-study-shows-100240/

5 ComScore. (2011A), op. cit.

6 Harvard Business Review Analytics Services. (2010). *The New Conversation: Taking Social Media from Talk to Action*. Retrieved from: http://www.sas.com/resources/whitepaper/wp_23348.pdf

7 Spina, A. (2010A). *Whytest Evaluation Report*. ACON, Sydney.

8 Spina, A. (2010B). *Drama Down Under Phase 2 Evaluation Report*. Australian Federation of AIDS Organisations, Sydney.

9 ComScore. (2011A), op. cit.

10 ibid.

11 Harris Interactive. (2011). *Social Networks, Blog Popularity Remain High for Gay Americans over Past Three Years*. Retrieved from http://www.prnewswire.com/news-releases/gay-and-lesbian-adults-are-more-likely-and-more-frequent-blog-readers-98317299.html

12 Spina, A. (2010A), op. cit.

13 Spina, A. (2010B), op. cit.

14 ComScore.(2011B). *The Power of Like. How Brands Reach and Influence Fans Through Social Media Marketing*. p. 2. Retrieved from: www.comscore.com/like

15 ComScore. (2011A), op. cit.

16 ibid.

17 Stokes Mischewski Market Research Sydney. (2012). *The Big Picture Evaluation Report*. ACON, Sydney.

Yves Calmette is Principal Program Planner at ACON.

THE STATE OF SOCIAL MEDIA USE IN NON-PROFITS IN AUSTRALIA

Bianca Worth provides a preview of new research that surveyed almost 600 Australian non-profit organisations about their use of social media; 65% of the organisations examined were health and human services based. The survey report aims to generate a reflection of how non-profits are using social media specific to the Australian context.

Let's pretend we are at a party. At this party there are people milling about chatting, establishing relationships, relaxing with a cool beverage or partying on the dance floor.

The party is called 'Social Media'.

At this party there are some well-known celebrities and high flyers, people you have seen at other parties, people you know well and other people you wouldn't have a clue who they were.

You weren't going to come to this party but a friend called you and said you absolutely have to be in on this. It's the latest thing. Everyone is doing it. Haven't you been yet? Gosh, you need to get with it!

But you still didn't know if this party was for you. Wouldn't it be great if you knew before you arrived what everyone was wearing, who would be there and how popular they are, where they are from, if they are going to talk to you and how to make a fast exit?

Let's get the intel before we get dressed in our party gear.

Prepping for the party

When this research project commenced it did so with the knowledge there were questions that were repeated over and over again whenever we presented on social media to community groups, to

small business, to non-profits, and even to big corporates. Questions we couldn't answer specifically for Australia. Oh sure, we gave them the latest statistics from overseas but it's kind of like a party that you hear about, but never attended – it sounds great but maybe not your kind of scene. Similarly, there is plenty of social media research based on international organisations but Australia seemed to be lacking some real proof on how social media was actually being used by non-profits.

After starting with a long list of questions, they were narrowed them down to just four that encompassed answers to the most important:

- Is social media use really prolific in the Australian non-profit sector?
- Which social media technologies have the strongest use?
- How do non-profits typically use social media?
- Who are the top ranked non-profit organisations using social media in Australia?

Who is at the party?

Over the course of a few months data was collected, statistics were analysed, and pretty graphs were created.

First, let's take a look at the technologies covered and the high level results.

Social media as a whole covers thousands of technologies, tools and websites globally. Different social media websites and technologies are more popular in certain countries and locales. For example, Qzone is a Chinese language social media site with over 530 million users. Habbo in Finland has over 230 million users. Warning, warning Facebook: you're not the only one out there!

If you search on the internet for a health industry term such as 'HIV social media' you'll find thousands of results including social networks for HIV-positive singles, organisations using social media to promote their specific cause and mobile applications designed to help promote positive health awareness.

With such a huge scope to work from, it was important to select those most likely to be in use in Australia. As such the research focused on:

- Website presence
- LinkedIn
- Facebook
- YouTube
- Twitter
- Blogs
- Flickr
- Google+
- Vimeo
- MySpace
- 'Other'.

An international snapshot

Before we delve into the specific non-profit statistics, a brief review of some of the global statistics will help put them in perspective.

Let's start with Facebook. As of April 2012, they had over 901 million user accounts globally and an estimated 13 million unique visitors to the Facebook website in Australia. Facebook advertising indicates there are almost 11 million registered users. But, as with any statistics, you need to take these numbers with a grain of salt – people create multiple accounts so the actual registered users figure is like to

be at less. And this gives no indication of frequency of use or how engaged users are.

Moving on to Twitter with over 500 million registered users – Twitter themselves admit there are only 140 million active users. In Australia, the Twitter website receives around 1.8 million unique visitors a month.

LinkedIn is in a similar sphere with around 2 million registered users in Australia, and 96 million worldwide.

Newcomer Google+ recently announced they have 170 million registered users globally however like each of the others, the real figures in terms of actual use could be considerably lower.

Report findings

Our report, *The State of Social Media Use in Australian Non-Profits*, analysed just under 600 Australian non-profit organisations, with the majority (65%) being health and human services based. Organisations were classified into annual revenue streams of up to $253 million and employed anywhere from zero to almost ten thousand staff.

The research, due for official release in June, used mainly secondary data sources to collect information about almost 600 non-profit organisations and how they used social media including posting frequency, customisation, fans and follower statistics and their presence, or lack of it, across multiple popular social media platforms.

Based on usage tendencies, the report also identified and ranked the top 19 non-profit organisations that utilise social media the best, in comparison to the remainder.

The research found that 97% of non-profits have a website presence. Being an established online marketing medium, this wasn't really a surprise. Neither was the fact that LinkedIn, Facebook, YouTube and Twitter were the four social media technologies that ranked next highest in use.

What did come a surprise is that non-profit organisations earning between $100,000 and $250,000 were the least likely to use social media, where organisations earning less than $100,000 or over $5,000,000 were the most likely to use social media. However, organisations with more than one thousand staff were least likely to use blogs than any other classification of employed staff.

Where are they from?

Many social media platforms allow audience targeting through location based advertising, searches and/or posts. This allows organisations to better segment their audience through techniques such as location specific posts, offers, competitions or promotions. But did the location of the organisation's head office affect which social media technologies they chose? Apparently so.

The location of most organisations' head offices in this study were Queensland, New South Wales and Victoria. Queensland topped the highest use of Twitter, while NSW won out on YouTube and Google+ and came head to head with Victoria on Facebook use. Victoria took out first place with LinkedIn use and blogging.

What are they wearing?

Most social media platforms provide the ability for organisations to customise their page or mini-site with their own branding and tools. For example, Facebook allows imagery, logo and a custom URL for pages, as well as the ability to embed custom applications such as polls, donations, e-commerce, games and competitions, to name just a few. Twitter and YouTube are more limited as their platforms aren't currently built to accommodate on-page third party applications, however they do allow customisation of the background, colours and logo.

Customisation is an important aspect of online media to reinforce an organisation's core message, allow

instant recognition, and generate credibility through the consistency and commonality of the organisation's branding across dispersed platforms. Customisation on the Facebook platform in particular with applications allows the organisation to bring together the disparate social media platforms into a 'mini-website' by enabling website, Twitter and YouTube integration for example.

The research found that almost 50% of Twitter and YouTube accounts were customised, with Facebook sitting lower at 32%.

Within Facebook Pages, 15% integrated YouTube, 12% of organisations integrated their Twitter accounts, and only 5% integrated their website in some form (for example RSS streaming of blog posts) indicating many organisations are failing to optimise the potential integration and subsequent increase in visitors and engagement across these sites.

Are they going to talk to me?

One of the most often asked questions we are asked in any seminar, workshop or training is 'how often should I post to social media?'

The reality is that posting to social media is often more trial and error than a definitive science. Organisations setup social media accounts for different reasons and with varying focus. Their goals differ and so do their audience demographics. With this come differences in the acceptable number of posts before overwhelming (or underwhelming) visitors. This is all complicated by general lack of data around how often and when individuals actually log on and engage on each of these platforms. These are the reasons why testing is your best answer.

Broadly though, our research found that on average organisations posted to Facebook around three times a week versus eight times on Twitter. Facebook also had a higher average

number of fans at 2,500, versus Twitter at 570 followers. However, the fact that Twitter had a higher number of posts per week also alludes to the fact it is a more dynamic and fast paced online communications medium.

Within the research, we also analysed some of the top posters in the non-profit sector. ACON topped everyone with 108 Facebook posts in a month, while the University of Adelaide gets a blue ribbon for tweeting more than 890 times in a month.

Making a fast exit

One of the most interesting areas of the study was learning which social media platforms had the highest abandonment rate. We would all know at least one organisation which tried social media and gave up on it because it didn't attract an audience (or the right audience), the engagement was low or non-existent, or the organisation simply underestimated the amount of time and effort that needs to go into social media to make it a successful marketing tool.

So which platform had the highest abandonment rate? It was the tool that has the potential to bring in the highest organic search engine optimisation (SEO) rankings, but also the one that would be most likely to require a greater investment in writing time – blogs.

31% of all the blogs analysed had no posts in the past three months. The figure dropped down to 6% for Facebook and 3% for Twitter. Google+ was 14%, however, as it is less than a year old it is likely much experimentation is still happening with this platform.

The video sharing platforms were considered 'abandoned' after two years as videos tend to require a higher initial time investment than text-based content and aren't created as often. As a result, YouTube had a 20% abandonment rate, followed up by 7% for Vimeo.

Given the data was collected based on what wasn't already in the taxi heading
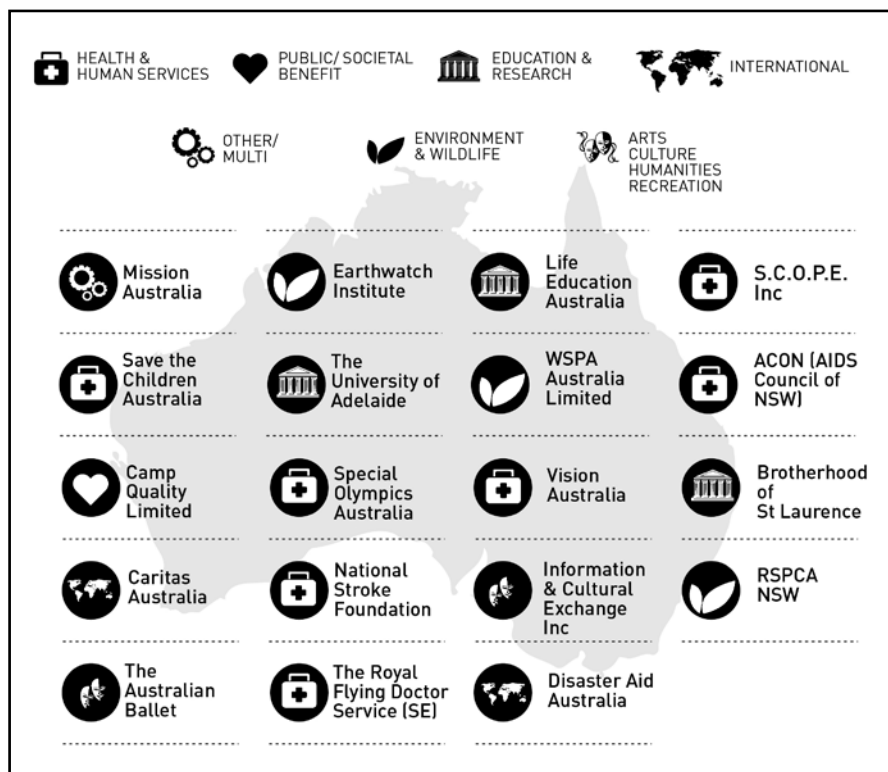
The top 19 non-profits

home at the time, it should be kept in mind that social media tools like Twitter and Facebook may have a higher abandonment rate and they are simply closed down once it is recognised they are not working as a communications medium for the organisation.

The morning after

Throughout this research, the goal was to provide some intelligence to the non-profit sector about what other organisations are doing in the glittery, music pumping, fast-paced party known as social media.

Based on the results of the research, we have three morning after coffee shots to choose from:

1. Test your conversation starters – you have some baseline statistics to work from, now test the frequency and messaging – even changing punctuation or asking a question will bring different results in posts, video descriptions and titles.

2. Go matchy matchy – yes it's a terrible fashion faux pas in the real world but at the social media party, consistent branding will help further your online goals and reinforce your brand.

3. Seek to meet your target market – don't just go to the party where are the popular people are going. Go to the one where the people you want to reach are hanging out.

Have fun!

Sources

Wirth Consulting, Google Ad Planner, Facebook, Google Blog, Twitter, LinkedIn Blog

Bianca Wirth is the Director and Lead Consultant at Wirth Consulting, a company that specialises in online technology research, analytics, development and training. If your organisation would like to obtain a copy of the complete research report or participate in future online technology research, please contact Bianca Wirth blwirth@wirthconsulting.com.au

LINKED IN: CONNECTING DATA TO ENHANCE RESEARCH

By Dean Murphy

Information about health is recorded throughout people's lives as they come in contact with the health system. Much of this information is kept in databases by health departments, hospitals, and other organisations. Record linkage is the task of identifying records corresponding to the same entity from one or more data sources.[1] Linking to records that already exist is relatively quick and provides data for populations that would be prohibitively expensive to collect in any other way. These endpoints include diagnosis of notifiable diseases, hospitalisations, emergency department presentations, or even death. Record linkage allows for the possibility of conducting sub-studies looking at predictors of specific clinical outcomes or endpoints within a particular population.

Data linkage can be conducted at study, institutional, regional or state/national level. Some jurisdictions, notably the province of Alberta in Canada, have extensive linkage of health and increasingly also social data. In Australia, linkage has been used for health and medical research in Western Australia since the 1970s and is now coordinated by a collaboration of academic and health institutions and the state department of health. The WA Data Linkage System was established in 1995 to connect all available health and related information for the WA population. In New South Wales, the Centre for Health Record Linkage (CHeReL) was established in 2006 and is jointly managed by the Cancer Institute NSW and the NSW Ministry of Health. The CHeReL undertakes linkage between research projects and existing health databases.

Linkage can also be made between data and biological specimens or genetic material. Human tissue collected in individual studies can be stored and used in the future to link back to the demographic and other data collected from the individuals concerned. Perhaps the most famous example of record linkage was the ill-fated Icelandic Health Sector Database (HSD) in which the genome of the Icelandic population was to be matched with medical records to determine genetic predictors of health outcomes.[2] This information could then be leveraged for profit by a private company, deCODE genetics who would commercialise the results of the research which it was hoped would lead in particular to the development of pharmaceutical products. The Icelandic biobank was built on an opt-out model in relation to the inclusion of people's medical records.

An example of data linkage is the *45 and Up Study*, which is a study of ageing in which over 250,000 men and women aged over 45 from across NSW – about 10% of this age group – have been recruited for prospective follow-up. Information is collected via a baseline questionnaire from participants selected at random from the Medicare Australia enrolment database (with oversampling of residents in rural areas and those aged 80 years). A follow-up questionnaire is mailed every five years. The study involves linking to medical records including data from the NSW Admitted Patient Data Collection, Medical and Pharmaceutical Benefits Schedule (MBS and PBS) datasets, NSW Central Cancer Registry and Australian Bureau of Statistics (ABS) mortality data.

HIV research and data linkage

In HIV-related research, linkage is also common. Linkage can be conducted between studies of people living with HIV and existing databases to determine associations between data collected in studies and particular health outcomes – for example, whether patterns of antiretroviral use are associated with increased or decreased morbidities. Additionally, linkage can be conducted to more accurately determine risk of HIV acquisition within particular groups. For example, Jin et al. (2008)[3] conducted linkage to determine HIV incidence among a cohort of gay men in addition to HIV acquisition determined through testing

> In HIV-related research, linkage is also common. Linkage can be conducted between studies of people living with HIV and existing databases to determine associations between data collected in studies and particular health outcomes – for example, whether patterns of antiretroviral use are associated with increased or decreased morbidities.

at the annual study visits. Each year, identifiers, including name code (first two letters of the first and last name) and date of birth, from participants were matched against the national HIV register to identify HIV infections that occurred in those who tested outside the study, or who had been lost to active follow up. A total of 22 HIV infections were determined in this way compared to 31 through testing in the study.[4] This shows the importance of linkage because in its absence the cohort study would have reported a lower incidence. In another study by Pierce et al. (2011)[5], men in Victoria who had received HIV post-exposure prophylaxis (PEP) were similarly matched against the Victorian HIV Surveillance Registry to determine incidence among previous users of PEP.

Online and offline consent

Linkage between data collected directly through clinical research or interviewer-administered surveys and health records is one thing but linkage from data collected online to health records is very uncommon and still viewed with suspicion, largely because linkage generally requires explicit consent based on a signed consent form. This seems to be based on an assumption that people are not fully aware of what they are consenting to online, and that it is difficult for researchers (and ethics committees) to determine if a participant has understood the informed consent statement. However, an analysis by Varnhagen et al. (2005)[6] found no difference between online and offline studies. They suggest that online studies actually offer opportunities to improve consent. Arguably, online research poses less risk to participants because reduced social pressure makes it easier for participants to withdraw if they feel discomfort i.e. 'active continuous consent'.[7,8]

In 2009, as part of a study to determine the feasibility of an online cohort study of gay men, a survey was conducted that explored men's willingness to allow linkage to health-related data and whether willingness was associated with any demographic

or behavioural characteristics.[9] The survey focused on attitudes to linking with databases of HIV/AIDS, STIs, hepatitis, cancer, Medicare records, and death. Among 1,135 men eligible participants from all states and territories (9% of whom were HIV-positive), only 47% said they would be willing to join a part of the study consisting of record linkage. (However, nearly a quarter of the others were unsure rather than refusing outright, which possibly reflects a general lack of familiarity and inadequate understanding of record linkage.) There were few differences between responses to different registries.

Participants were also asked which identifiers they would be willing to provide to facilitate record linkage. Most participants indicated they would be willing to provide their postcode (92%) and date of birth (83%). In relation to other identifiers there was a direct relationship between the perceived personal nature of the information and willingness to disclose. The proportion of respondents who would be willing to provide the first two letters of their given name or the first two letters of their family name was 76% and 70% respectively (and only 48% would be willing to provide the first two letters of both their given name and the first two letters of their family name). A sizeable proportion (26–29%) indicated that they were unsure if they would be willing to provide these minimal identifiers. Less than 10% expressed an outright refusal

to have their data linked to any register. About one-third indicated they would be willing to provide their full name or Medicare number.

The factors influencing willingness to provide a minimal identifier varied between HIV-negative and HIV-positive men. Among HIV-negative men, those who were willing to provide a name code were older and more likely to identify as gay. Men holding a university degree had a tendency to be more reluctant to provide these key identifiers. Among HIV-positive men, those who were willing to provide key name code identifiers were older and had a tendency to be less educated. HIV-positive men who reported any unprotected sex with casual partners were less likely to be willing to provide key identifiers. This may suggest some concerns related to disclosing information about unprotected sex in the context of the increasing tendency in some jurisdictions to criminalise of HIV transmission.

HIV and eLinkage: the challenges

The challenges to linkage to HIV-related records are both practical/technical and ethical. Some health databases contain full names, which in conjunction with dates-of-birth would allow for deterministic rather than probabilistic linkage. However results from the survey mentioned above

Linkage between data collected directly through clinical research or interviewer-administered surveys and health records is one thing but linkage from data collected online to health records is very uncommon and still viewed with suspicion, largely because linkage generally requires explicit consent based on a signed consent form.

demonstrate that only about one-third of men would be definitely be willing to provide full names for this purpose. It seems feasible and acceptable to request name codes and dates-of-birth from participants. This does not preclude linkage to other databases such as the National Cancer Database and the National Death Index. It means, however, that these databases would need to be customised for linkage which involves additional costs.

An online study does not mean that consent is less thorough than in other study design – in fact it is likely that the opposite may be true. However, inquiries to data custodians and experts in record linkage (such as CHeReL and Australian Institute of Health and Welfare) about whether online consent would be sufficient for linkage did not produce any definitive answers. It is likely that this will only be known by making an application to ethics committees. What seems certain however is that linkage between individual studies and Medicare data is logistically and ethically complex as well as prohibitively expensive. Although the *45 and Up Study* for example links to Medicare, this study is set up in a way mentioned above that allowed this, such as the selection of participants from the Medicare Australia enrolment database,

as well as an insistence on signed consent (including a physical audit of signatures). Consent to data linkage was also a prerequisite, rather than an optional consent, for participation in the study.

Conclusion

Linkage between health records is increasingly common and contributes to accuracy of health and epidemiological data. These data are kept in largely electronic databases in health departments, hospitals, and other organisations. Paradoxically, research data collected electronically in the form of online surveys and cohorts presents a problem for data linkage in that permission to undertake linkage studies is traditionally dependent on informed consent, based on a signature. There is a suspicion that consent obtained online is less thorough than consent obtained in person, or even by return mail. However, recent research has suggested that online consent is comparable to consent obtained through traditional means.

Australian gay men seem relatively willing to provide information that would allow for linkage to existing health databases. This willingness may be the result of trust built up over three decades of HIV-related research and would be interesting to

compare to other populations. Not surprisingly, willingness to provide information is inversely related to its identifying nature. In addition, among HIV-positive men who reported any unprotected sex with casual partners there was less willingness to provide identifiers for data linkage, which may indicate concerns related to disclosure of these practices.

References

1. Lifang, G., Baxter, R. (2006). Decision Models for Record Linkage. In Williams, G. and Simoff, S. (Eds.) *Data Mining, Lecture Notes in Computer Science*, 3755, 146–160. DOI: 10.1007/11677437_12 3755

2. Pálsson, G. (2008). The rise and fall of a biobank: the case of Iceland. In Gottweis, H, Petersen, A. (Eds.) *Biobanks: Governance in Comparative Perspective*. Routledge, Abingdon, UK.

3. Jin, F., Prestage, G., McDonald, A., Ramacciotti, T., Imrie, J., Kippax, S., et al. (2008). Trend in HIV incidence in a cohort of homosexual men in Sydney: data from the Health in Men Study. *Sexual Health, 5*, 109–112.

4. Jin, F., Jansson, J., Law, M., et al. (2010). Per-contact probability of HIV transmission in homosexual men in Sydney in the era of HAART. *AIDS, 24*, 907–913.

5. Pierce, A., Yohannes, K., Guy, R., et al. (2011). HIV seroconversions among male non-occupational postexposure prophylaxis service users: a data linkage study. *Sexual Health, 8*, 179–183.

6. Varnhagen, C., Gushta, M., Daniels, J., et al. (2005). How informed is online informed consent? *Ethics & Behavior, 15*, 37–48.

7. Pequegnat, W., Rosser, B., Bowen, A., et al. (2007). Conducting internet-based HIV/STD prevention survey research: considerations in design and evaluation. *AIDS & Behaviour, 11*, 505–521.

8. Sproull, L ., Kiesler, S. (1991). *Connections: New ways of working in the networked organization*. MIT Press, Cambridge, MA.

9. Adam, P., Imrie, J., Murphy, D., et al. (2009, September). *A national gay men's Internet based prospective cohort and behavioural surveillance platform in Australia—results of a feasibility and acceptability study*. Paper presented at the 21st Australasian HIV/AIDS Conference, Brisbane.

> There is a suspicion that consent obtained online is less thorough than consent obtained in person, or even by return mail. However, recent research has suggested that online consent is comparable to consent obtained through traditional means.

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

ELECTRONIC HEALTH RECORDS: TAKING CONTROL OF YOUR E-HEALTH FUTURE

By Michael Frommer

From the 1 July 2012, all Australians will be able to begin using their own Personally Controlled Electronic Health Record (PCEHR). Consumers will have a choice whether to opt-in to the system.

The scheme has been in development for some time and there are great expectations about its potential. In particular, a comprehensive e-health system promises great benefits for people living with HIV, given that people living with HIV have complex health needs and are frequent users of the health system. However, some questions are yet to be addressed and concerns remain – including around the readiness of consumers, health providers and the system itself, to meet expectations.

The Australian Federation of AIDS Organisations (AFAO) has been heavily engaged with the e-health consultation processes with the aim of ensuring the needs of people living with HIV are met. This article discusses what we currently know about how e-health records will operate – including features that will give users greater control over their personal information – and what questions remain unanswered.

PCEHR: the basics

The PCEHR is designed to give individuals an electronically accessible medical history that both they and their approved health providers can access throughout Australia. The PCEHR will complement practitioners' existing medical records with additional information[1], while also according the consumer precise controls over what their PCEHR contains and who has access to the information.

The PCEHR interface will allow healthcare providers, as authorised by the consumer, to see an overview of allergies/adverse reactions, medicines, pathology tests, medical history, immunisations, directives, recent health care events and pathology and radiology reports. Pathology and radiology information and results will not be available with the initial rollout. According to the PCEHR design document – *The Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System* ('the Concept of Operations') – the aim is to have these available from large private sector laboratories by 30 June 2013 and other providers by 30 June 2014.[2]

According to the National E-health Transition Authority (NEHTA), the PCEHR[3]:

- will bring together key health information from a number of different systems, and present it in a single view
- will allow information to be accessed by the individual and their authorised health care providers. Over time the individual will be able to contribute to their own information and add to the recorded information stored in their individual record
- will not hold all the information held in the individual's health care professional's records but will complement those records by highlighting key information, and
- in the future, as it becomes more widely available, the scheme will allow individuals to access their own health information from anywhere in Australia.

Consumer controlled levels of access

At the core of the PCEHR system is a user controlled 'access list' which controls which organisations are permitted to access an individual's records. The PCEHR offers consumers the choice of two levels of control over the access list – *basic* and *advanced* access controls.[4]

> The PCEHR interface will allow healthcare providers, as authorised by the consumer, to see an overview of allergies/adverse reactions, medicines, pathology tests, medical history, immunisations, directives, recent health care events and pathology and radiology reports.

For people living with HIV – who may wish to maintain confidentiality and privacy around their HIV status – it is vital that they understand these options in order to feel confident about exercising control over their personal information.

Consumers will be able to administer these access settings at any time via an online portal, which will be accessible at the newly launched www.ehealth. gov.au. This will enable people to confidentially vary settings to levels they feel are appropriate at any time. Consumers will also be able to ring a call centre to manage access list settings, as well as:[5]

- make general inquiries about the PCEHR System and the registration process
- resolve issues around using the PCEHR System
- resolve complaints, and
- provide feedback around the PCEHR System.

The online portal also contains a public learning centre which was, at the time of publication, undergoing maintenance. Community organisations should check here for any useful resources and tools that may help our communities. Over time, individual consumers will also be able to contribute to the information stored in the PCEHR themselves.[6]

Basic access

Under 'basic access', any healthcare organisation involved in the care of the individual is automatically added to the access list of the PCEHR, unless the individual requests otherwise.[7] However, control over which documents are stored on the record remains with the individual; where they express a preference not to upload a particular document, the healthcare provider should not do so.[8]

Advanced access

Additional access control settings can also be administered by the individual which provide greater control over who has access to information stored in their PCEHR. These settings include the ability to[9]:

- **Set up a Provider Access Consent Code (PACC).** The PACC is effectively a PIN number which the individual is able to give out to healthcare providers at their discretion. If the individual chooses to set up a PACC, then organisations will not be able to add themselves to the access list unless they have the PACC.
- **Restrict organisations from being on the access list**, and
- **Prevent a PCEHR from being found.** Individuals will be able to determine if they want their

PCEHR to be 'findable' or not. If the individual chooses for their PCEHR to be 'not findable', upon arrival at a healthcare organisation not currently on the access list, any search for their PCEHR will return 'not found'.

Similarly, if the organisation is marked as 'revoked' on the access list then it will not be able to find the individual's PCEHR. By default, a PCEHR will be findable, unless the individual changes this setting; however, a PCEHR can still be found with emergency access if the individual has selected this option.[10]

- **Manage document level access.** If an individual enables PACC pin access on their record they will also be able to control which organisations can access individual documents stored on their record. They will also be able to describe what level of access each organisation on their access list is granted to each document – either 'general access' or 'limited access'.[11]

'General access' means that the clinical document will be accessible by any healthcare organisation who has been granted PACC access. 'Limited access' means the clinical document is only available to a more limited group of healthcare organisations. The clinical document is still accessible to the healthcare organisation that supplied it. 'Limited access' can also be overridden by a healthcare provider in an emergency situation.[12]

Once a document has been marked 'limited access', by default it will not be viewable by any healthcare providers. In order to allow a particular, trusted healthcare provider to view it, an individual must create another pin, called the PACCX. This can be provided at the consumer's discretion.[13]

> For people living with HIV – who may wish to maintain confidentiality and privacy around their HIV status – it is vital that they understand these options in order to feel confident about exercising control over their personal information.

Effective removal of clinical documents

The PCEHR System will support a process called 'effective removal', in the event that a clinical document has been loaded into a PCEHR which should not be there. This includes events such as[14]:

■ **Identification error:** the healthcare organisation has inadvertently misidentified the individual in the clinical document.

■ **Clinical information error:** the healthcare organisation has supplied incorrect information and the clinical document needs to be removed.

■ **Individual-initiated removal:** the individual did not wish the clinical document to be included in their PCEHR.

Documents can be 'effectively removed' either though the call centre or the online consumer portal. According to the Concept of Operations, if the individual requests a clinical document be 'effectively removed' from their PCEHR, they will be required to indicate that they understand the implications of its removal (namely that the clinical document will no longer be accessible via their PCEHR and this may mean the individual may not receive the benefits of having this information available via their PCEHR in future episodes of care).[15]

Issues for consideration

Criminal implications

It is important to note that although documents that have been 'effectively removed' are locked – preventing further access by an individual or their healthcare providers (including using emergency access)[16] – this does not appear to prevent access by people at the back-end. According to the Concept of Operations 'an effectively removed document remains accessible

to the PCEHR System Operator … only be accessed for legal reasons.' This leaves open the door for authorities to access 'effectively removed' documents in the event that individuals are subject or party to legal proceedings, such as criminal investigations of alleged exposure or transmission of HIV.[17]

Clause 70 of the *PCEHR Bill 2011* stipulates that the System Operator may disclose health information to law enforcement agencies for prescribed purposes set out in sub-clause 70(1); these include the 'prevention, detection, investigation, prosecution or punishment of criminal offence or breaches of certain other laws'.[18] AFAO believes that this discretion is too broad and that this may result in law enforcement authorities 'fishing' for evidence possibly contained in a person's PCEHR.

The investigation relating to potential criminal prosecutions of people with HIV in relation to the sexual transmission of or exposure to HIV is a case in point. Providing access to health/medical information for the purpose of prosecuting criminal matters or resolving civil legal disputes should be subject to court-ordered subpoena rather than the System Operator's discretion, and should relate to particular information rather than

to general information contained in a person's PCEHR.

Furthermore, as the Concept of Operations states, effectively removed clinical documents will be able to be accessed for legal reasons. HIV sector organisations are thus left in a quandary as to how to guide our constituents. Specifically, are we able to confidently advise people that by exercising the 'effective removal' mechanism, any record thus removed containing information regarding HIV status, sexual history or injecting drug-use, is safe from being accessed by authorities? If so, how do we communicate this? If the answer is 'no' – or the more, likely 'currently unknown' – should our advice err on the side of caution to not upload any such information in the first place, as there is a chance that authorities may be able to search PCEHRs?

Consumer rights and remedies

It is essential that consumers are able to control and monitor their record, and where appropriate, can pursue a remedy.

In some circumstances it might be clearly apparent that sensitive information has been inappropriately disclosed. For example, if in the course

> Specifically, are we able to confidently advise people that by exercising the 'effective removal' mechanism, any record thus removed containing information regarding HIV status, sexual history or injecting drug-use, is safe from being accessed by authorities? If so, how do we communicate this?

of treating their patient a health worker was to remark, 'I'm sorry to hear that you have HIV, how did it happen?' However, in other scenarios an instance of unauthorised disclosure might be less clear.

Hypothetical case study

Angelique, an HIV-positive African woman, chooses to have HIV-related discussions only with her s100 subscriber, discussing all other health matters with the family GP. During a consultation with her GP about her children's health, she notices subtle but perceptible changes in the GP's behaviour and attitude. Here, the ability to view the audit trail of a record may help Angelique identify if the family GP did inappropriately access her PCEHR.

The Audit Trail – a crucial protection

AFAO advocates both for the provision of a thorough audit trail recording access to PCEHR, and crucially, the right for consumers to access this record. It is pleasing to see that the legislation provides robust provisions guaranteeing access to the audit trail.

The ability to see an audit trail of who has accessed and handled their PCEHR should provide individuals with greater confidence in the system. In a situation where someone is concerned that they may be receiving inferior and/or discriminatory health care, such as in the scenario faced by Angelique, they will be able to check if the healthcare provider has indeed become privy to personal information that they shouldn't have. If this has occurred, they could choose to raise the matter with the provider informally, or pursue a formal complaint.

Complaints

The Information Commissioner will be able to receive complaints in relation to any act or practice the breaches the *PCEHR Bill*.[17] The Bill will treat any contravention as interference with

privacy under the Privacy Act. This is a positive development, as the *Privacy Act 1988*[19] has general limitations, which would otherwise stymy its capacity in some circumstances to investigate, such as restrictions on its jurisdiction over records held by state/territory bodies.

Where something doesn't necessarily breach the PCEHR legislation it may still be possible for a complaint to be made to the relevant professional body. If someone is disclosing sensitive information in a casual conversation, based on what they saw sitting on computer monitor, this may be subject to professional disciplinary proceedings.

Other issues

Other issues requiring further attention include:
- Lack of e-health conformant infrastructure in hospitals, and for allied health professionals
- Some resistance from healthcare providers in engaging in the system. For example, the Australian Medical Association (AMA) has expressed concerns about using the record where it may not be comprehensive. The AMA guide to the PCEHR[20] has advised GPs to reconsider engaging with the e-health record if their patients have restricted availability to some documents.
- Paucity of practical consumer information, beyond the very general. Detailing real-life use of the PCEHR will be essential to establishing trust of consumers generally – particularly those with stigmatising conditions such as HIV.

Conclusion

The PCEHR is almost upon us, and there is much to welcome, including the fact that consumers will eventually be able to gain access to a range of their health information. However, expectations for the July rollout should be modest. Initially, only some types of information will be available,

while at the same time only certain healthcare providers will be willing and able to participate in the system. Most significantly, the HIV sector must be able to confidently advise our members/constituents of the system's pros and cons, including the risk that information collected may be able to be accessed contrary to an individual's will, for legal/investigative purposes.

References

1 *What is a PCEHR?*. National E-Health Transition Authority. Retrieved from: http://www.nehta.gov.au/ehealth-implementation/what-is-a-pcher
2 Department of Health and Ageing, *Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System*, Canberra, September 2011, 55. Retrieved from: http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/CA2578620005CE1DCA2578F800194110/$File/PCEHR-Concept-of-Operations-1-0-5.pdf
3 *What is a PCEHR?*, op. cit.
4 Department of Health and Ageing, op. cit.
5 ibid.
6 National E-Health Transition Authority website, op. cit.
7 Department of Health and Ageing, op. cit.
8 ibid.
9 ibid.
10 ibid.
11 ibid.
12 ibid.
13 ibid.
14 ibid.
15 ibid.
16 ibid.
17 ibid.
18 *Personally Controlled Electronic Health Records Bill 2011, Explanatory Memorandum*, 54. Retrieved from: http://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r4738_ems_f076ddf7-5345-448d-9115-c120e217a462/upload_pdf/362618.pdf;fileType=application%2Fpdf#search= legislation/ems/r4738_ems_f076ddf7-5345-448d-9115-c120e217a462
19 *Privacy Act 1988*. Retrieved from: http://www.austlii.edu.au/au/legis/cth/consol_act/pa1988108/
20 Australian Medical Association (2012, April 12). *Draft AMA Guide to Using the PCEHR*, point 6.1.7, 18. Retrieved from: http://ama.com.au/draft-ama-guide-using-pcehr

Michael Frommer is Policy Analyst at AFAO.

GOVERNMENT 2.0

By Jason Appleby

Background and introduction

Online communication has undergone a paradigm shift within the last decade. This shift, collectively referred to as 'Web 2.0', is characterised by a set of principles and practices[1] that have seen dissemination of information online move from a 'read only' model using static, centralised websites (a 'one way' or 'top down' approach) to a more decentralised, collaborative model of sharing that privileges user generated content alongside the opinion of subject matter 'experts'.

Over time, Web 2.0 has been used more as a marketing term than a computer-science-based term. Blogs, wikis, and web services are all seen as components of Web 2.0. For example, the website YouTube attracts not only people wanting to view content which has been professionally produced, it also allows for the immediate sharing of videos by individuals who wouldn't otherwise produce content.

This proliferation of Web 2.0 technologies and the growth of the internet have changed the way many people live their lives. As the exchange of information and ideas becomes easier, and as people become connected in ways undreamed of twenty years ago, expectations around the accessibility of information have reformed to reflect this.

While entire industry practices have evolved in step with these technologies, the reticence of government (and government agencies) to harness the potential of the web has been often noted. The concept of 'Government 2.0' is about government departments making use of Web 2.0 technologies to encourage a more open and transparent form of government, where the public has a greater role in forming policy and has improved access to government information.

Government and the Web 2.0 paradox

As the Australian Government itself has noted, the concept of Government 2.0 is based around a paradox[2].

All the most popular collaborative Web 2.0 platforms – including blogs, wikis and social networking sites such as Wikipedia, Google, Facebook and Twitter – function like community assets, given that they are available for public use without charge. Although the platforms have been developed by commercial companies they conform to the technical definition of public goods because[3]:

- they are freely available; no-one is excluded from enjoying them, and
- one person's enjoyment of them does not hamper others' enjoyment of them – indeed it typically enhances it.

Recent change

Early changes to government practice, largely focusing on enhancing service delivery and communication to the public using Web 2.0 tools, have been lauded as increasing the efficiency and effectiveness of government agencies. For example, in many countries, up to 70% of tax returns are filed via the internet, and many transactions can be purchased or paid for online.[5] However, further engagement by government departments with internet-based technologies and services (particularly those displaying Web 2.0 characteristics such as user generated content) has been slower to develop. Partially this is because government,

and the bureaucratic practices which support it, require environments of accountability and control. The internet and particularly the much vaunted Web 2.0 technologies, act to connect many to many. Government communication relies on more authoritative one to many broadcast regimens. The internet removes and reduces the ability to censor or control which creates a tension between government needs and broader social desires.

Government 2.0 in Australia

Since 2008, there has been significant cultural pressure for Australian Government agencies to utilise web (and similar) technologies to improve and increase the way in which governments communicate (and become accountable) to society.

The Government 2.0 movement (known more widely as Gov 2.0 – a reference to the .gov domain names associated globally with government agencies) has embodied several key principles, mainly relating to increasing accessibility to government held and maintained data.

During 2009–2010 the Australian Government formed a Taskforce to provide advice and evaluate evidence for embracing Government 2.0 values. It was formed against a backdrop of increased interest by governments worldwide in the potential uses of public sector information and online engagement. The formation of the Taskforce coincided with the completion of a six month trial of online consultation in government.

The Taskforce provided a full report to government (which is available online at http://agimo.govspace.gov.au/2010/05/03/response-to-the-government-2-0-report/) during 2010. The Taskforce's report recommended changes to a range of areas, including coordinated leadership, guidance, support and recognition for agencies

and public servants engaging online, and the important considerations of accessibility and security.

In response to the findings of the Government 2.0 Taskforce, in May 2010 the Australian Government provided a response which embraces the findings and recommendations of the Taskforce.

Australia joins countries such as the United Kingdom and United States in having clearly articulated principles which describe a commitment to more open government.

Declaration of Open Government

At the heart of the Government 2.0 Taskforce's report was the recommendation that the Australian Government makes a declaration of open government.

Lindsay Tanner, as head of the Government 2.0 Taskforce, made the following declaration in July 2010[4]:

> *The Australian Government now declares that, in order to promote greater participation in Australia's democracy, it is committed to open government based on a culture of engagement, built on better access to and use of government held information, and sustained by the innovative use of technology.*
>
> *Citizen collaboration in policy and service delivery design will enhance the processes of government and improve the outcomes sought. Collaboration with citizens is to be enabled and encouraged. Agencies are to reduce barriers to online engagement, undertake social networking, crowd sourcing and online collaboration projects and support online engagement by employees, in accordance with the Australian Public Service Commission Guidelines.*
>
> *The possibilities for open government depend on the innovative use of new internet–based technologies. Agencies are to develop policies that support*

employee–initiated, innovative Government 2.0–based proposals.

The Australian Government's support for openness and transparency in Government has three key principles:

- ■ *Informing: strengthening citizen's rights of access to information, establishing a pro–disclosure culture across Australian Government agencies including through online innovation, and making government information more accessible and usable;*
- ■ *Engaging: collaborating with citizens on policy and service delivery to enhance the processes of government and improve the outcomes sought, and*
- ■ *Participating: making government more consultative and participative.*

Challenges particular to health promotion

The unique nature of health data, and the laws which restrict access to it (to the *Commonwealth Privacy Act* for example) have frequently been seen as obstacles to Gov 2.0 in the health promotion arena. Key data collections which may have other uses are restricted by law, or principle, and are not easily accessible. To date, efforts to release truncated versions of these data sets for broader use are generally unsupported.

In addition, health related data sets tend not to be designed with consideration to Open Access principles. There are significant differences between and within State and Federal government agency data collections that inhibit the useful aggregation and common use of this data.

There are also significant challenges to enabling the open release of government maintained information. The Government 2.0 Taskforce notes that[5]:

> *If governments are to become part of this world – as contributors and users of the vast potential of Web 2.0,*

their culture must encourage it. Right now it does not. Before government engages – whether it is by way of communicating with the public or releasing information – a panoply of permissions is required. In any but routine service delivery roles, officials are typically not authorised to speak to the public without substantial clearance processes.

Instead of being immediate, government announcements and actions can take some time to be forthcoming while all possible stakeholders are consulted and points of view are considered. Instead of being informal, governments tend to speak formally with each word chosen very carefully. Government processes are intended to minimise the chance of making a mistake with little regard given to the potential costs this imposes on innovation.

Conclusion

Health (and health promotion) services are yet to fully explore and realise the potential of internet based technologies such as Web 2.0. This is largely due to traditional government processes which focus on accountability and control. The Government 2.0 philosophy may act to enable and extend health promotion as information traditionally managed and owned by government becomes more accessible.

References

1   O'Rielly, T.(2005). *What Is Web 2.0?*. Retrieved from http://oreilly.com/web2/archive/what-is-web-20.html
2   Australian Government Information Management Office – Department of Finance and Deregulation, *Engage: Getting on with Government 2.0 – Report of the Government 2.0 Taskforce, 2009*.
3   ibid.
4   Tanner, L. (2010). *Declaration of Open Government*. Australian Government Department of Finance and Deregulation Retrieved from: http://agimo.govspace.gov.au/2010/07/16/declaration-of-open-government
5   Baumgarten, J., Chui, M. (2009). *E-government 2.0*. Retrieved from: http://www.i-gov.org/images/articles/11138/egov20.pdf

Jason Appleby is the Treatment Editor for *HIV Australia*.

RESULTS FROM THE STIGMA AUDIT: A SURVEY ON HIV STIGMA IN AUSTRALIA

By Sean Slavin

Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic. There have been various studies of HIV stigma internationally and many attempts to combat it, with mixed success. At the same time many people working in the area emphasise the haziness of the issue. Both experiences and ideas about what stigma is can vary from one person to the next. Stigma is a concern because it compromises the human rights of people living with HIV, affecting their health and well-being just as the virus does. Stigma also affects prevention efforts because it makes it less attractive for HIV-negative people to get tested.

Last year NAPWA (the National Association of People Living with HIV/AIDS) undertook a project to try and understand stigma in an Australian context. It conducted an online survey and a number of interviews with people living with HIV to try and get a better sense of their concerns. The project aimed to: generate an evidence base for combating HIV-related stigma so as to improve health outcomes for people living with HIV and support ongoing prevention efforts; build awareness about stigma and social research among HIV-positive people using a participatory model of research; translate the research findings into practical and useful recommendations for community based HIV/AIDS organisations, policymakers, government advisory groups and relevant health services; and provide a rigorous measure of HIV stigma that will inform the implementation of the *Sixth National HIV Strategy* and provide evidence for the development of future national strategies.

Twenty-seven interviews were conducted by peer interviewers and 697 people completed the survey. Survey respondents included 662 men, 32 women and three transgender people. Roughly 85% identified as gay men and this is broadly representative of the Australian epidemic. People's year of diagnosis varied from 1981 to 2011, with the average being 1999. Four-fifths of the sample were on treatment and the average year of commencement was 2002. About one-third said they had noticeable symptoms of HIV. Two thirds said their quality of life was good or very good and a little over half said they were satisfied or very satisfied with their health.

When measuring stigma we used an internationally respected scale that, once analysed, showed a moderate experience of stigma among respondents. Some examples of the questions we asked in the scale and people's responses were: 34% agreed with the statement 'I feel guilty because I have HIV'; 77% agreed with 'Telling someone I have HIV is risky'; 35% disagreed with 'I never feel ashamed of having HIV'; 42% agreed with 'I work hard to keep my HIV a secret'; 40% agreed with 'most people think that a person with HIV is disgusting'; and 40% agreed with 'I have been hurt by how people reacted to learning I have HIV'.

We also asked people about their experiences with HIV treatments: 42% agreed with the statement 'If I go to an HIV clinic I am concerned that someone might see me'; 47% agreed with 'I avoid taking my meds in public'; 42% agreed with 'I worry that people might see me collect my meds from the pharmacy'; 64% agreed with 'I am concerned that if I have physical changes from HIV meds people will know I'm HIV-positive'; and 61% agreed with 'I worry that side effects can make my status apparent'.

When we looked at the characteristics of people who experienced greater amounts of stigma they were more

> Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic. There have been various studies of HIV stigma internationally and many attempts to combat it, with mixed success. At the same time many people working in the area emphasise the haziness of the issue. Both experiences and ideas about what stigma is can vary from one person to the next.

likely to be single, have a lower level of education, report noticeable symptoms of HIV and experience stress, depression or anxiety. People with less experience of stigma were more likely to be resilient, have good self esteem, be satisfied with their health, have good quality of life and good social support and be more likely to engage in HIV community.

We also asked respondents to tell us who and where they had disclosed their status. The highest levels of disclosure tended to be in the more intimate areas of life – sex, family and friends – as well as healthcare settings. There were lower levels of disclosure in more public arenas of life – work, housing and community.

When we asked in which arenas of life people had experienced most stigma, by far the most common responses were in relation to sexual partners, community and the media. Given that about 85% of the sample were gay men and said they identified with gay community, this suggests that we still have quite a bit of work to do here. A number of people have noted the irony that more stigma exists in the one place we would hope to find greater understanding and tolerance.

In conclusion, it is important to note that not all people living with HIV experience stigma and this is encouraging. It is also worth noting that HIV-positive people are not immobile in the face of stigma but avoid it in certain ways – especially by managing their identity and carefully choosing the contexts in which they disclose. As we move into the next phase of the project that aims to turn the research into practice we will be exploring ways to better support the resilience of people with HIV so that stigma has less of an impact.

This article originally appeared in the March 2012 edition of *Positive Living* magazine, published by NAPWA.

Sean Slavin is Assistant Director and Manager of Research Programs at the National Association of People Living with HIV/AIDS (NAPWA).

AFAO AND *HIV AUSTRALIA* ONLINE

👍 **Read *HIV Australia* online for additional content not available in the printed edition: www.afao.org.au**

👍 **Find us on Facebook: http://on.fb.me/afao-facebook**

👍 **Visit the AFAO Talks blog where we share information about AFAO's involvement with HIV events in Australia and internationally: afaotalks.blogspot.com/**

👍 **Visit AFAO's YouTube channel for a range of HIV-related content: http://www.youtube.com/user/AFAOMedia**

👍 **Visit our Slideshare page to access presentations from AFAO conferences and events http://www.slideshare.net/AFAO**

FEAR LESS LIVE MORE: DEALING WITH HIV STIGMA AND DISCRIMINATION ONLINE

By Simon Donohoe and Ben Tart

It's no surprise that HIV-related stigma and discrimination remain major barriers to dealing effectively with the HIV epidemic in Australia and around the world. The impact of stigma is not only felt by individuals living with HIV but also has direct consequences on Australia's public health response to the epidemic by undermining prevention, care and treatment efforts. HIV stigma can deter people at risk of acquiring HIV from being tested, and deter HIV-positive people from accessing appropriate treatment and care. Stigma and discrimination also remains the main obstacle preventing people living with HIV from disclosing their status to friends and family, employers and work colleagues, health care providers and insurance companies; not to mention prospective sexual and/or romantic partners.

The issue of HIV-related stigma and discrimination has not been directly addressed through any social marketing campaigns in Australia for over a decade and – possibly more importantly – there has been a distinct lack of hard-evidence showing how, and to what extent, HIV-related stigma and discrimination is enacted and experienced within Australian gay communities. The little research that does exist, such as the Barometer Survey conducted by AFAO and the National Centre in HIV Social Research (NCHSR) in 2009, indicates that HIV-related stigma is most commonly experienced by gay men in sexual and romantic settings.

Furthermore, social marketing campaigns that have occurred in the past have targeted the mainstream Australian community about their prejudicial attitudes towards people living with HIV and AIDS; however, until the release of the AFAO–NAPWA Fear Less Live More campaign on World AIDS Day 2011 (1 December) there had not yet been a national campaign that speaks directly to gay men and other men who have sex with men about prejudices that exist around sexual and romantic relationships within our gay communities.

Fear Less Live More campaign elements

In recognition of the complexity of the task in addressing HIV stigma and discrimination, AFAO and its member organisations have developed and released a multi-pronged campaign titled Fear Less Live More.

The over-arching aim of the campaign is to encourage gay men to communicate more openly about HIV in the context of sex and relationships. The campaign uses a mix of print and online strategies to focus on five areas: communicating about HIV status; choosing casual sex partners; acknowledging concerns about HIV; negotiating serodiscordant relationships; and overcoming fear of rejection.

Fear Less Live More is being distributed nationally by AFAO and its membership; campaign materials include a website, posters, web banners, a short animation video, print ads, postcards and t-shirts.

At the heart of the campaign are a suite of five posters combining text and hand-drawn illustrations designed by award-winning artist Jim Tsinganos. These posters were developed out of the campaign research and were designed to encourage men to think about and debate the themes raised by the campaign materials.

To facilitate interaction and discussion around the campaign themes, a Facebook page and a website (www.fearlesslivemore.org.au) were created, providing additional information about the campaign's focus areas. The website allows users to take part in conversations with each other on the site, as well as encouraging people to

The impact of stigma is not only felt by individuals living with HIV but also has direct consequences on Australia's public health response to the epidemic by undermining prevention, care and treatment efforts. HIV stigma can deter people at risk of acquiring HIV from being tested, and deter HIV-positive people from accessing appropriate treatment and care.

join the Facebook page and continue discussions there. The audience is able to engage with the campaign in a variety of ways, including joining, 'liking', providing comments and sharing stories in an effort to harness and help shape a community standard of non-discriminatory behaviour. A short animation video, entitled 'Ever found yourself in a closet?', supports this goal by making a link between HIV-related stigma and experiences of homophobia. The video also helps drive traffic to the website and Facebook page.

The Facebook page itself includes two sub-pages, each designed to encourage engagement and interaction. The first page relates directly to the content of the video animation, while the second encourages people who are – or have been – in a serodiscordant relationship to share there story by posting a message (or video/photograph) demonstrating the existence and strength of such relationships.

Site statistics show that, to date, over 1,000 unique users have interacted directly with campaign messages though Facebook or the Fear Less Live More website. Comments are monitored by AFAO staff, however the moderation style aims to take a 'hands-off approach' as much as possible to allow online community the space to debate issues themselves and operate as a 'self-correcting' community. This approach has proved very successful, and has allowed a range of comments about people's experiences and interpretations of campaign messages – both positive and negative – to coexist. While comments about the campaign are not universally positive, numerous people have left appreciative messages supporting the campaign. To date, AFAO staff have not needed to intervene or remove comments.

Campaign development

During the development of the campaign, an initial series of focus groups found a broad range of factors influencing the ways HIV stigma and discrimination was enacted and experienced. The research also found that these instances appeared to be on the increase – especially in both potential and realised sexual and romantic relationships. It seems there are less reasons for gay men to come together as a coherent community. These reasons include greater social acceptance of diverse sexualities and related legal reforms which have allowed many gay men to mix more freely in mainstream society (including in social venues). This, as well as the improved health and wellbeing of positive people in general, has led to HIV-negative men having less conscious interaction with HIV-positive people (not to mention mainstream, heterosexual community members).

The sharing of online spaces

Changes to the way gay men relate to one another in physical spaces have occurred alongside the evolution of online social spaces.

It is well known that online forums have become a main way in which many gay men meet. The anonymity offered by online interaction can result in individuals feeling freer to voice opinions in ways they may not do in face-to-face situations – this includes discriminating against someone on the basis of specific characteristics such as their HIV status. The ease of screening potential sexual partners online based on HIV status ('serosorting') is often as simple as looking for a checked box in a person's profile. It is quite likely that this online phenomenon has also contributed to serosorting becoming a more common and 'acceptable' practice in physical situations.

One of the key things we learnt about how HIV-positive and HIV-negative men interact in shared online spaces was that profile descriptors commonly used on gay men's chat sites were interpreted in a variety of ways. For example, there did not appear to be a consistent interpretation across age range or HIV status about what is meant by 'wanting bareback only', or what is meant when someone's profile reads 'Always', 'Never', or 'Needs discussion' in relation to using condoms. This could strongly perpetuate discrimination because learning that someone is HIV-positive after interpreting their online profile as implying that they were HIV-negative could reinforce an individual's negative perceptions of HIV-positive people in general.

How HIV-status affected campaign engagement

The development process for Fear Less Live More highlighted that social marketing alone will not achieve the required shifts in attitudes among HIV-negative (and status unknown) gay men. This has been reinforced through an initial analysis of the online engagement of the campaign, particularly through the campaign's Facebook page.

Most comments and posts placed on the Facebook page were from HIV-positive men. We found that HIV-negative gay men were less likely to visibly engage with the online component of the campaign and, in particular, were less likely to participate in Facebook threads by posting and/or 'liking' comments.

The Facebook component of the campaign seemed most successful in being able to:
1. Provide encouragement and support for HIV-positive gay men around HIV stigma and discrimination, and
2. Reinforce and strengthen existing resilience of HIV-positive gay men around stigma and discrimination.

Outcomes and recommendations

The online component of Fear Less Live More, particularly the Facebook page, may have overreached in its ambition by 'trying to do all things

for all people'. While there was a strong engagement by HIV-positive men, the Facebook page appeared to lack in active engagement by HIV-negative men. However, it is much harder to quantify the number of 'passive readers' that may have engaged with campaign messages.

Overcoming fears

Overcoming fears of HIV-positive partners is a step-by-step process for many HIV-negative men. The first step for many HIV-negative men is to start talking about HIV; for it to be a topic of discussion in general, rather than something that is not discussed except by HIV prevention campaigns.

The next step in HIV-negative men in overcoming their fears is in knowing HIV-positive men socially. Personally knowing someone with HIV acts to 'humanise' the condition and begin the educative process on other sides to HIV and people living with HIV (PLHIV), rather than only the need to prevent transmission.

Additionally, knowledge that serodiscordant relationships are able to occur and do exist is important. The inclusion of serodiscordant couples within the focus groups identified a number of key lessons that could be used in future work of AIDS Councils and PLHIV organisations. The most important of these was that knowledge of a serodiscordant couple is one of the key educative experiences for young men to overcome some negative assumptions they have towards HIV.

The final step in overcoming fears of having HIV-positive sexual partners was for HIV-negative men to educate themselves on all of the risks associated with sex.

Campaign materials therefore, need to be programmatically supported through concurrent group-work interventions, community outreach, individual counselling and other community initiatives. These additional supporting activities will need to be

One of five Fear Less Live More campaign posters, illustrated by Jim Tsinganos

regularly rolled out through AIDS Councils and PLHIV organisations over the coming years.

Online social/sexual networking spaces that allow the opportunity for HIV-positive men to share thoughts and experiences may however, assist in equipping positive men with the skills and resilience to better withstand and combat stigma and discrimination.

Join the conversation by visiting http://www.fearlesslivemore.org.au or find us on Facebook.

Ben Tart is Health Promotion Officer at AFAO. Simon Donohoe is Manager of the AFAO–NAPWA Education Team at AFAO.

STANDING UP AND FINDING MY VOICE THROUGH POSITIVE DIGITAL STORYTELLING

By Sonja Vivienne

'Positive Stories' is a digital storytelling initiative that took place in Adelaide in 2010–2011.[1] This article describes participants' experiences of creative self-representation and the thorny complications of mediating voice, particularly in situations where privacy and publicity are significant issues.

Digital stories are short (3–5 minute) autobiographical documentaries, usually driven by a first-person narrative. They typically combine elements such as voice-overs, still photographs, artworks, and other personal documents with sound effects and music to communicate stories about people's lived experiences.

Digital storytelling is typically a workshop-based practice, where participants learn to tell their own stories while strengthening their communication skills and digital media production techniques. As a movement, digital storytelling emerged from the empowerment through community arts discourses popular on the west coast of the US in the late eighties.[2] The Center for Digital Storytelling (CDS) formalised the process and it was later championed in the UK as a tool for bringing the voices of 'ordinary' people to mainstream audiences via the BBC.[3]

As digital technologies for production (digital cameras, computers and editing software) and distribution (DVD and online) have become more accessible many advocates have noted the democratic potential of the medium. For individuals whose stories are marginalised, misrepresented or ignored by mainstream media, digital storytelling offers an opportunity for self-representation. However, for many storytellers, regardless of these *potentials*, the realities of stigma and discrimination (in both on and offline communities) can have a significant influence upon the kind of content people are willing to share and how and with whom they share it. Additionally the manner in which workshops are framed and facilitated by organisations can also influence the content that participants produce, and what they are willing to say.

'Positive Stories' overview

'Positive Stories' is a collaboration between 'Incite Stories'[4], the AIDS Council of SA (ACSA) and Feast Festival (the annual GLBTQI cultural festival in Adelaide) with financial support from SA Health. The project was initially conceived as a community theatre piece in which newly diagnosed HIV-positive people (diagnosed within the last 10 years) would be invited to create and perform experiences of seroconversion and living with HIV. Due in part to a lack of interest from prospective participants, the project steering committee acknowledged that it might be problematic for some people to share stories of recent diagnosis, risk behaviour and its consequences in such a public fashion. The initiative was re-conceptualised as a digital storytelling project, as this would give participants the option to conceal their identity while also reaching a wider audience than a theatre project could.

While the project aimed to engage a younger community who were 'slipping through the cracks' of other educational outreach work, recruitment of this target group proved difficult. After an extended period and a loosening of the original parameters a modified workshop process was designed to accommodate the needs of a small group of storytellers – three men and one woman. The initiative stretched out over an 18-month period – partly as a result of the recruitment process – however, this extended time frame also accommodated fluctuating health and energy levels and allowed storytellers to commit technically, creatively and emotionally on their own terms. The storytellers were highly engaged in the production of their stories and worked alongside professional editors who undertook the final cut under each storyteller's direction.

The 'Positive Stories' DVD collection was launched in 2011 at a community screening and discussion forum during the Adelaide FEAST Festival (South Australia's largest annual GLBTQI cultural event). The stories are available to purchase on DVD from ACSA, and can also be rented from the Darling House Community library.[5] They were screened during the 2011 Adelaide Fringe Festival and are being submitted to a variety of film festivals. They have an online presence at www.rainbowfamilytree.com (a queer digital storytelling community website) where they can easily be shared with other online social networks such as Facebook and Twitter. The storytellers are empowered in this distribution process as they elect who they wish to share their stories with and whether they choose to be identifiable or anonymous.

Public and private identities

Digital story production and distribution can be challenging, particularly as one considers the ramifications of 'being public' and 'being private'. Making a digital story is in many ways a construction of self. However, while most of us are accustomed to tweaking our identity performances for a variety of audiences in a variety of social contexts[6], the knowledge that these stories would eventually circulate online for years to come highlights

the dilemmas of what has come to be known as 'social convergence'[7] – where different audiences and time frames are collapsed into the same context.

The 'Positive Stories' workshops were characterised by many discussions on the risks and benefits of being 'out and proud' about living with HIV. Even storytellers who felt that the benefits of increased community awareness (and potential social change) outweighed the risks of disclosing personal information online were nevertheless mindful of the impact their story might have, for example, on a nephew or niece if it were viewed by the parents of a school-friend ('His uncle's a FAGGOT! His Uncle's got AIDS!'[8]).

While 'blurring' faces is a familiar de-identifying technique, for many people it has criminal or shameful connotations, so a variety of creative methods to conceal individual identities were explored. These included using artworks, playful 'masking', staging re-enactments, choosing music and pacing editing to evoke mood rather than focusing on identifying details. In this way digital storytelling, unlike many other forms of personal 'everyday activism'[9], allows individuals to have a voice in the public sphere while nevertheless retaining the anonymity they require in order to feel safe.

Mediating voice

The relationship between workshop participants, facilitators and editors creates a complex co-creative dynamic where stories are moulded through suggestions and critiques. The five stories created during the 'Positive Stories' initiative are slicker than many digital stories, due in part to the substantial input of the talented and experienced editors. A delicate balance was struck between maintaining a raw 'authentic' storyteller voice and producing a 'professional' product that might engage a broader audience.

These collaborations produced some unexpected results. For instance, a cynical 'vent' was collectively transformed into 'Greg's Sermon', a dance floor anthem for young men

not sure how to 'love themselves'. In another case, a storyteller who was quite keen to retain creative control found that ongoing health issues made mastering the editing software difficult. Instead, he opted to channel his creative energies into coordinating and directing a dramatic and cathartic recreation of a violent encounter with homophobia.

The dilemma of how best to represent, distil or translate the semantic intentions of a storyteller is one that has been wrangled by many documentary filmmakers, anthropologists and scholars. Barbara Myerhoff achieved both acclaim and notoriety for the creative approach to anthropology she used in bringing the stories of an elderly Jewish community to mainstream audiences in book and documentary form, ('Number our Days', Myerhoff, 1978). Myerhoff proposes use of a kind of 'third voice' 'which is neither the voice of the informant nor the voice of the interviewer, but the voice of their collaboration'.[10] Kaminsky critiques Myerhoff:

> "'… collaboration" mystifies the fact that in her attempt to conceptualize her writing practice, ultimate semantic authority resides with the anthropological author and that in actuality the informant who yields her words to the interviewer neither collaborates in text production nor knows what turns her words will be given in the author's hands.'[11]

Narrative therapists (many of whom cite Myerhoff's collaborative practices as inspiration[12]) and some researchers and documentary makers deal with the complex issue of mediating voice by 'checking back in' with the speaker, thereby offering them the opportunity for final clarification. However, it is interesting to note that most documentaries or research projects in which a final product has been funded or endorsed by an institution require that participants sign a legal 'release form' that forgoes any 'right of approval' over how they are represented. From an institutional point of view this avoids the onerous process of achieving consensus and allows the producers/researchers/

broadcasters/publishers to focus upon producing a marketable product. Community development initiatives tend to have a greater focus on an empowering process rather than a marketable product and 'Positive Stories' followed in this tradition while nevertheless aiming for educational and engaging end products that would have social impact. Story content was discussed collaboratively (with other storytellers, workshop facilitators and ACSA support staff) throughout the development process with the main priority being to facilitate clear expression of each storyteller's intentions. Each storyteller retained copyright over their story while licensing them for use by ACSA in a DVD compilation, at a launch screening and on their website.

The issues of 'mediating voice' are amplified in situations where privacy and publicity are of paramount concern, a fact that workers in the HIV sector are well aware of. From the framing of the 'Positive Stories' initiative itself, to the form and content of each story, to the wording of publicity materials for the launch at FEAST and at Adelaide Fringe, time was taken to seek input from and prioritise the voices of the storytellers, an approach that was conscientiously and consistently undertaken by all of the assorted stakeholders, from facilitators and editors, to ACSA support staff.

Conclusion

Practical recommendations that have emerged from the 'Positive Stories' initiative, include: 1) engaging with community members regarding the framing and objectives of the initiative; 2) allowing an extended flexible time frame; 3) negotiating both individual and collective co-creative practices; and 4) privileging of the 'quieter' (marginalised) voice. An extended time frame allows for complex and evolving discussions between storytellers and the networks of friends and family
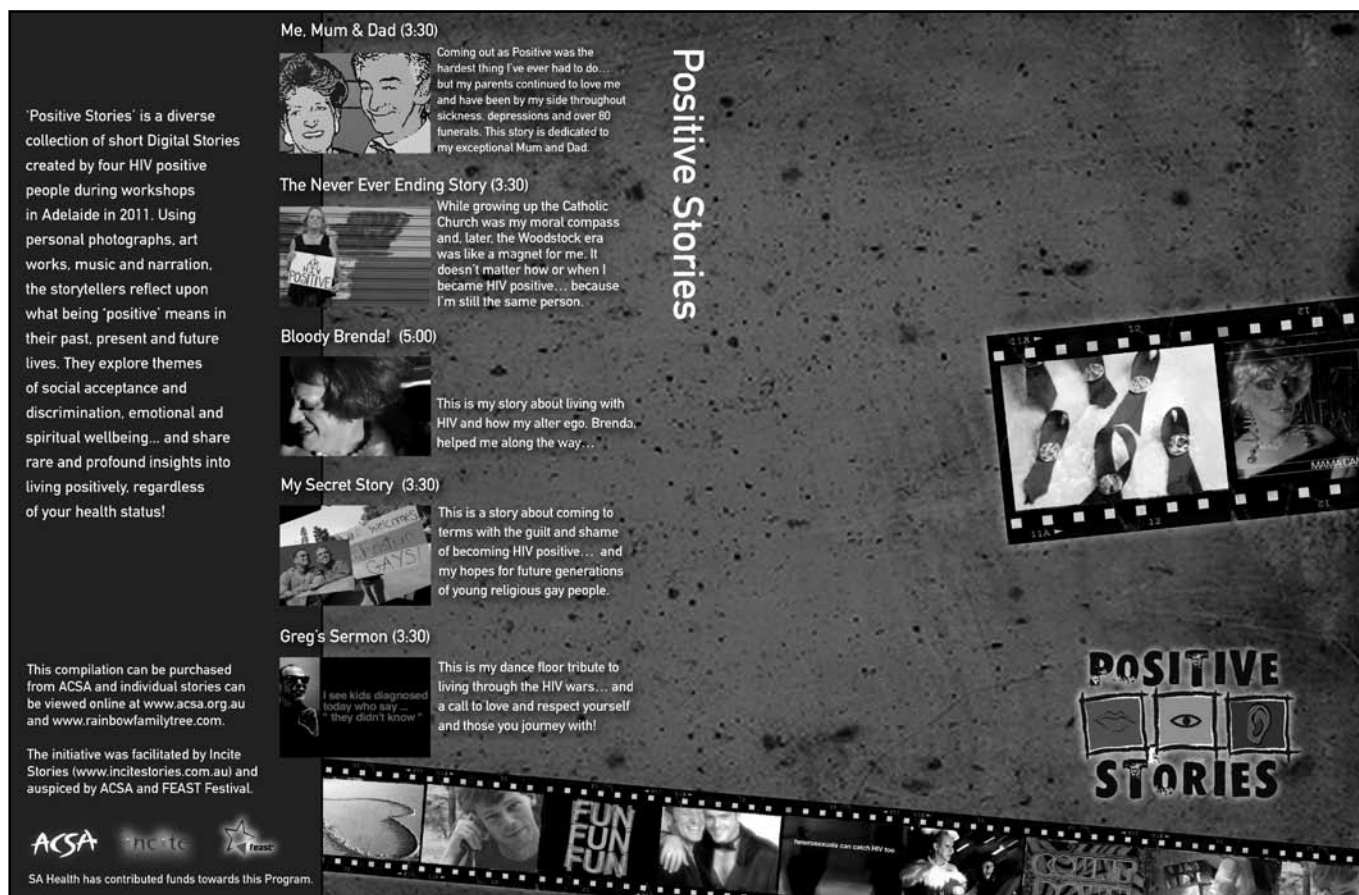
The 'Positive Stories' DVD cover

that also have some kind of stake in the process and product. Regardless of whether the storyteller is the principal editor or director of the story, a longer post-production period allows for revisions in the final edit and a greater likelihood that the storyteller will 'own' the final product that they then 'have to live with' – an imperative if the storyteller is to experience any degree of self-empowerment.

Negotiations around co-creativity and the privileging of the storyteller's voice requires self-awareness on the part of all facilitators, regardless of whether their role is one of logistic, technical, creative, or financial support. The 'step up/step back' principle first articulated by the architects of the early digital storytelling movement are useful to keep in mind: that is, if you are aware that you are often the proactive or talkative 'leader' of a group … step back. If you are aware that you are often the quiet 'observer', step up. This practice of conscious listening is pertinent for participants,

facilitators and auspicing organisations alike. Having said that I'll leave it to a storyteller to 'speak the final words' from which this article's title is also derived:

> *'I feel it's been an incredibly rewarding experience to* [share] *my stories … It's one of the few things I've done in connection to 20 plus years of being positive where the end result was NOT …"there you go dear you poor little AIDS victim, we will do this and do this and do this for you" … it's the one thing that I've walked away from and actually felt empowered by because I've learnt skills and it sort of forced me to stand up.'* ('Positive Stories' participant, group evaluation, 2011).

References

1   This paper emerges from a PHD research project that explores Digital Storytelling as a tool for 'Everyday Activism' in particular issues of 'queer identity', 'voice' and 'imagined publics'. It is positioned in a nexus between Cultural Studies, Internet Research and Queer Theory and uses 'observant participant' methods as part of an ethnographic approach.

2   Lambert, J. (2009). Where it All Started: the Centre for Digital Storytelling in California. In Hartley, J. and McWilliam, K. (Eds.), *Story Circle: Digital Storytelling Around the World*. Wiley-Blackwell, West Sussex, UK, 91–117.

3   Meadows, D., Kidd, J. (2009). Capture Wales: The BBC Digital Storytelling Project. In Hartley, J. and McWilliam, K. (Eds.), *Story Circle: Digital Storytelling Around the World* (pp. 91–117). Wiley-Blackwell, West Sussex, UK, 91–117.

4   www.incitestories.com.au

5   Available at: http://acsa.intersearch. com.au/cgi-bin/koha/opac-detail. pl?biblionumber=8855

6   Goffman, E. (1959). *The Presentation of Self in Everyday Life*. Anchor Books, New York.

7   boyd, d. (2008). Facebook's Privacy Trainwreck: Exposure, Invasion, and Social Convergence. *Convergence: The International Journal of Research into New Media Technologies, 14*(1), 13–20.

8   Interview with participant, 2011.

9   The author uses 'everyday activism' to connote the use of personal stories in public spaces by 'ordinary' people in pursuit of social change.

10   Kaminsky, M. (1992). Myerhoff's 'Third Voice': Ideology and Genre in Ethnographic Narrative. *Social Text, 33*, 124–144.

11   ibid., 127.

12   For elaboration see White, M., Epston, D. (1990). *Narrative means to therapeutic ends*. A Norton professional book. Norton.

Sonja Vivienne is a filmmaker and PhD candidate at Queensland University of Technology. She is also creative principal of 'Incite Stories' (www. incitestories.com.au) and is particularly interested in digital cultures, queer identities and everyday activism.

RAISING HPV AND ANAL DYSPLASIA AWARENESS: HOW WE USED A 'FIRST BOOTY' NARRATIVE TO TOUCH HEARTS AND MINDS

By Mark Hubbard

Our story begins in the 1980s. Andrew, 25, has just relocated to a big city to seek his fortune:

> 'Last week I described how Andy discovered sex with me and how he went about discovering his gay self. I'm Andrew's anus, and I have HPV. Eventually, Andy and I discovered that we were shacking up with other viruses as well.
>
> I believe we could all help anuses stay healthier if we'd bring the subject out of dark nether regions and into the light of day. Most gay guys are fairly informed about HIV, but far too many know far too little about HPV (the human papillomavirus). Experts tell us that most people have been exposed to HPV, which can sometimes cause genital warts or lead to anorectal cancers.'

This excerpt is from *Andrew's Anus*, a first person, or rather 'first booty' narrative series I wrote for the LifeLube. org blog to raise awareness about HPV, anal dysplasia, and rectal health.

Despite being personally affected, it took a while for HPV to become an advocacy priority for me. That's partly because scientific understanding has remained incomplete and consensus illusive.

I believe that all advocacy must be grounded in human understanding. Any serious effort must be informed by the real world experiences of individuals – what happens to us, how we cope, and what we learn.

Lifelube.org had been established to deliver entertaining and engaging wellness information for gay and bi men. Jim Picket, the director of prevention advocacy and gay men's health at the AIDS Foundation of Chicago, was editing the blog in 2007 when he read my posts on a gay men's health e-list and encouraged me to contribute. I am by no means a professional writer, particularly in terms of discipline. Mostly I write when I feel passionate about issues or experiences. Over time I came to realise that the sharing of personal stories was what made the blog effective and popular.

> 'It was summertime and the Pet Shop Boys' second big hit *Opportunity* was Andy's theme song. It was playing at the club when he went out the night before leaving town. Andy was really pumped about his new job working for two up-and-coming gay entrepreneurs. He shook his moneymaker (and me) on the dance floor like there was no tomorrow.
>
> Andy was ecstatic in his new life – for a while. He loved his job, the city was really happening, and he met a hot new beau within a few days of arriving. The guy was a fish packer (seriously!) and built like a brick shithouse. Andy worshipped Patrick's Soloflex body and Patrick really loved "poking" me, as he called it. Andy loved that too, but he had to say no as often as he said yes just to keep from wearing me out.'

I grew more and more worried about my own HPV history. There was increasing concern about the emergence of pre-cancerous lesions in HIV-positive individuals. What most activists considered the best care – screening by high resolution anoscopy – could not be found in my region. I brought in an expert to speak to consumers and staff at the local HIV clinic, but change was not forthcoming.

I knew I was going to write something about these challenges, but just couldn't decide what or how. One night, as I was sitting with my ageing Dad at the dinner table in the suburban ranch house where I grew up, inspiration hit me.

My parents' house is full of *Readers' Digest* magazines, some decades old. I remembered that its editors commissioned articles designed to help people understand their bodies with titles like 'I'm Joe's Liver' and 'I'm Jane's Uterus.' That the story would be based on my own experiences had been a given. Writing as 'Andrew's Anus' would give me the courage to open up, ignore taboos, reject stigma, and celebrate the anus and rectum as valid centres of sexual pleasure.

> 'I'm tired of worrying about a couple of pre-cancerous spots in me, and Andy's downright pissed about the obstacles he's faced trying to get the right kind of care for me. He says part of the problem is that people aren't comfortable talking about things like anuses, rectums, and butt sex. I'm damned determined to change that, so I'm telling my story.
>
> Andy and I have been fuck buddies forever. We discovered we liked having sex about the time he learned to drive. I've been with Andy through decades of ups and downs, good times and bad times, lovers and tricks.'

The more I personally encountered barriers to competent anorectal care, the more motivated to write I became. Community awareness and understanding was severely lacking. HPV disease was reported to be progressing more rapidly in HIV-positive individuals. Maddeningly, there were still no national guidelines for screening and treatment.

As I began to write, it became clear that Andrew's story was not just about HPV, but about HIV and hepatitis B too. Although he'd sometimes experienced good care, Andrew faced discrimination, medical malpractice, and barriers to access. Medical vignettes were intertwined with relationship, substance use, and coming of age storylines, and the series seemed to become a microcosm of everything LifeLube had been about since its inception.

'At his next visit, Dr. Johnson checked Andy (and me) out more thoroughly. He noticed some swollen glands on the back of Andy's neck and a cluster of warts on me. Both were indications that something might be up with Andy's immune system. He hadn't even known I could get warts, much less that they were caused by a virus that could stick around for decades.

The doctor told Andy the swollen glands were a sign of infection. "It could be a number of things, including the virus that causes AIDS," he said. Because he had no treatment to offer and because discrimination was nearly certain, Dr. J. didn't recommend getting a test. Instead he advised Andy to act as if he (and everyone else) was infectious – just in case. His colleague examined me carefully and recommended outpatient surgery to remove the warts.'

I soon realised I had too much material for one post and began thinking in terms of a few instalments. I became conscious of the need for technical accuracy. I approached three trusted colleagues. Ross Cranston MD FRCP is a respected researcher and provider in the field.

Jeff Huyett MS APRN BC is a nurse practitioner who has been providing anorectal care for a couple of decades. Jeff Taylor is a research advocate on the drug development committee of the AIDS Treatment Activists Coalition and a community representative to the AIDS Malignancy Consortium. All are advocates for gay and bi men's health and all three agreed to review installments for accuracy.

Both Jim and I had begun to use Facebook in our advocacy and organising work. Together we leveraged public and personal email lists as well as Facebook groups and messages to generate interest. In addition to record setting traffic, our efforts yielded articles and links on other websites and blogs, including Adam4Adam. I participated via Skype in a live webcast on the topic as part of a regular regional wellness show for people living with HIV/AIDS. Educators and recruiters from respected clinics wrote that they would use the series as a tool. Most gratifying personally were notes from guys who declared 'that's exactly my story!' The seven instalments written to date remain among the most visited posts on the site.

After Andrew's initial anal wart outbreak is resolved and he achieves relative stability in terms of his HIV and hepatitis B, the series leaps into the new millennium and begins to address current issues around anal dysplasia.

We follow Andrew's Anus just to the point of making an appointment for a first high resolution anoscopy.

The series is currently on hiatus; planned future installments will relate how Andrew's Anus is screened and treated for high grade lesions. The series may also be used to increase awareness about the pressing need to fund a definitive randomised clinical trial that can be used as the basis for national standards.

Advocates and educators around the world know the value of using culturally relevant storytelling. Their efforts range from comic strips to theatrical performances and novellas. Some are the product of extensive development efforts that include expert review, workshops, focus groups and other forms of community guidance. *Andrew's Anus* reminds us that authenticity is key, and that this strategy is a good fit for grassroots initiatives at any scale.

Mark Hubbard is the educational liaison for the [USA] Tennessee Association of People With AIDS and the convener of the HIV Empowerment & Action League. He has been sponsored to attend the Conference on Retroviruses and Opportunistic Infections (CROI) for the last four years and was sponsored to attend the recent Microbicides 2012 Conference in Sydney, where he gave a presentation on 'Andrew's anus'. The entire *Andrew's Anus* series can be read at http://lifelube.blogspot.com. au/search/label/andrew's anus

LET'S TALK ABOUT IT! A NEW WEBSITE FOR GAY MEN

By Ben Wilcock
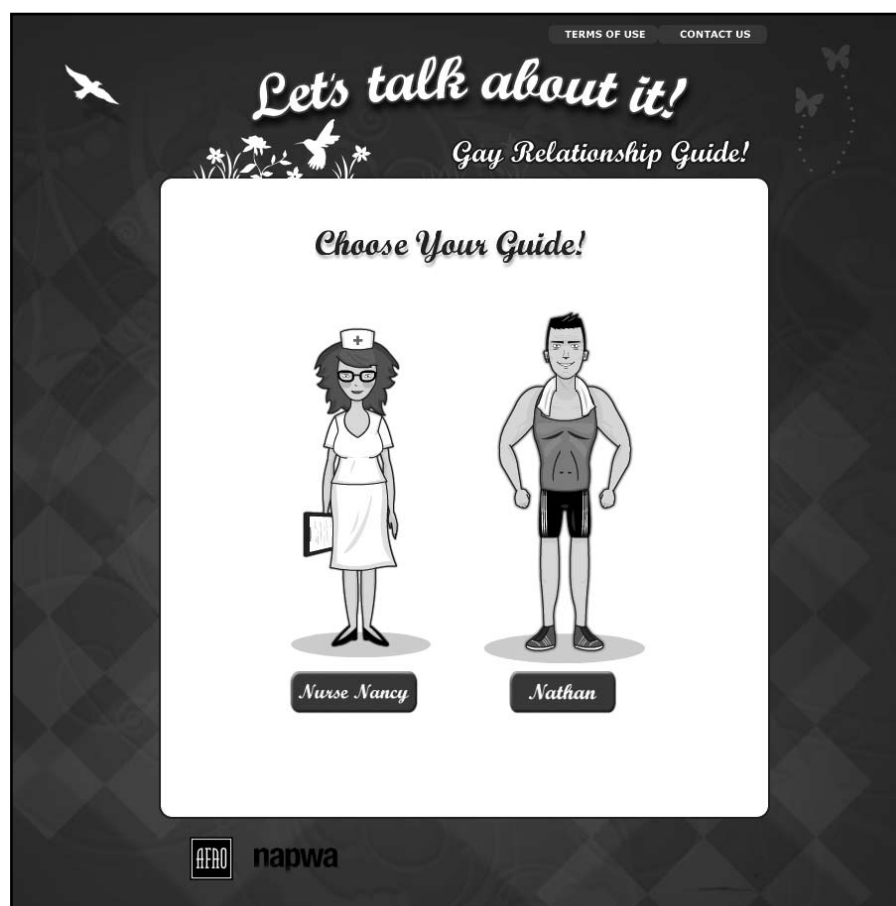
'Let's Talk About It!' is a new interactive website produced by the Australian Federation of AIDS Organisations (AFAO). The site is designed to help gay men to build healthier relationships by encouraging them to talk with their boyfriends or partners and help them come to agreements about their relationships.

It has been demonstrated that having an explicit agreement about sex within a relationship (as well as outside of it, if this occurs) is associated with greater relationship quality and satisfaction in general, regardless of the nature of the agreement.[1] Couples are also more likely to stick to the arrangement if they have a formal agreement in place, and maintaining these arrangements can help prevent the transmission and acquisition of HIV.

Negotiated safety is a term that refers to an agreement between HIV-negative men that limits unprotected anal intercourse (UAI) to only between partners within a regular relationship; any sex with other partners outside the primary relationship must be protected.[2]

Several studies have confirmed that having an explicit negotiated safety agreement is predictive of actual behaviour, both inside and outside the relationship.[3,4] It has also been demonstrated that men who don't have a clear negotiated safety agreement – especially those who had given up condoms on the basis of an *ad hoc* risk assessment without taking a test – were also much more likely to report inconsistent condom use with casual partners.[5]

A substantial proportion of men experience discomfort discussing sex and HIV with their regular partner, and this can cause problems in making clear and unambiguous agreements; this also hinders the ability for a partner to communicate breaches of the agreement if this occurs. Not surprisingly therefore, more effective communication between partners is associated with a greater likelihood of informing a partner in the event of a breach of an agreement.[6]

However, the number of gay men in relationships forming explicit relationship agreements about the sex they can have with each other, and with other men if they do, has been decreasing over time in Australia. The 'Let's Talk About It!' website has been produced in response to this decline to provide a tool to help gay men have these discussions and come to agreements in their relationships.

'A website that supports gay men in relationships to clarify and agree on their expectations is very timely,' explains Ian Rankin, President of AFAO, 'Social research shows that fewer couples are reaching these agreements. A clear understanding between partners promotes healthy relationships and reduces the likelihood of disease transmission.'

The 2011 *Annual Report of Trends in Behaviour* by the National Centre in HIV Social Research (NCHSR) reports that negotiated safety agreements between HIV-negative partners have been declining over time (see Table 1 overleaf).[7]

continued overleaf

Table 1 Negotiated safety agreements among HIV-negative men with HIV-negative regular partners: GCPS, 2001–2010

	2001 %	2002 %	2003 %	2004 %	2005 %	2006 %	2007 %	2008 %	2009 %	2010 %	Overall trend	Trend in last 3 years
Adelaide	43.4		32.1		41.9		35.4		30.6	33.1	↓	ns
Canberra			62.6			41.6			44.6		↓	—
Melbourne	43.6	32.7	33.8	37.7	38.4	37.5	28.7	38.9	33.3	32.3	↓	↓
Perth		28.6		22.2		35.5		29.6		23.7	ns	↓
Queensland	42.1	33.0	32.3	32.4	36.2		37.8	41.7	39.6	25.9	ns	↓
Sydney	43.8	49.9	37.8	48.3	31.8	33.1	30.5	36.0	28.5	33.8	↓	ns
All six states/ territories	43.7	37.7	35.6	35.6	35.6	35.3	32.4	37.9	33.2	29.7	↓	↓

Source: *HIV/AIDS, hepatitis and sexually transmissible infections in Australia: Annual report of trends in behaviour 2011*

However, 'Let's Talk About It!' is a resource for *all* gay men, not only men in relationships where both partners are HIV-negative. As Robert Mitchell, President of the National Association of People Living with HIV/AIDS (NAPWA) points out: 'There are many gay men living with HIV in relationships, both with HIV-negative men and other HIV-positive men. It is important for all men in relationships to have agreements for the health of both men in that relationship.'

A website was chosen as the mechanism for the resource because the format allowed information to be tailored to the circumstances of different gay mens' relationships. As the user progresses through the site, they are presented only with information based on the answers about their circumstances. This helps streamline the provision of information and creates an interactive experience for the user.

The user can further to tailor their experience on the website by choosing between two animated characters, 'Nurse Nancy' or 'Nathan' the personal trainer, to guide them through the information. The same information is provided by each character but in different styles or 'voices', a feature designed to add to the fun and interactive nature of the site.

This level of interactivity and tailoring of information aims to help gay men better engage with the site and the information provided, encouraging them to have discussions with their partners or boyfriends and help them come to agreements about their relationships.

The website is www.letstalkaboutit.org.au

References

1   Wagner, G., Remien, R., et al. (2000). Prevalence of extradyadic sex in male couples of mixed HIV status and its relationship to psychological distress and relationship quality. *Journal of Homosexuality, 39*(2), 31–46.

2   Holt, M., Ellard, J. (2011). *Literature review: HIV risk reduction strategies among gay men*. Australian Federation of AIDS Organisations, Sydney.

3   Moreau-Gruet, F., Jeannin, A., et al. (2001). Management of the risk of HIV infection in male homosexual couples. *AIDS 15*(8), 1025–1035.

4   Davidovich, U., de Wit, J., et al. (2000). Assessing sexual risk behaviour of young gay men in primary relationships: the incorporation of negotiated safety and negotiated safety compliance. *AIDS 14*(6), 701–6.

5   Moreau-Gruet, op. cit.

6   Prestage, G., Mao, L., et al. (2006). HIV risk and communication between regular partners in a cohort of HIV-negative gay men. *AIDS Care, 18*, 166–172.

7   de Wit, J., Holt, M., Hopwood, M., Treloar, C. (Eds.) (2011). *HIV/AIDS, hepatitis and sexually transmissible infections in Australia: Annual report of trends in behaviour 2011* (Monograph 3/2011). National Centre in HIV Social Research, The University of New South Wales, Sydney.

Ben Wilcock is a Health Promotion Officer at AFAO.

HIV AUSTRALIA

Got something to say?

Your views are important to the success of this publication.

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

DOWN AN' DIRTY: AN ONLINE RESOURCE FOR SEXUALLY ADVENTUROUS MEN (SAM)

By James May

Down An' Dirty (www.downandirty.org) is an online information resource and HIV prevention initiative of the Sexually Adventurous Men's (SAM) project – a joint venture between the Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC), People Living With HIV/AIDS (PLWHA) Victoria and the Australian Research Centre in Sex, Health and Society (ARCSHS). The project was established after research found an increased risk of HIV and sexually transmitted infections (STIs) among sexually adventurous men.

The behavioural attributes that define 'sexually adventurous' include: having multiple sex partners; being highly engaged socially and sexually with other gay men – particularly with HIV-positive gay men; having broad sexual repertoires and being sexually experimental; frequent use of illicit drugs and sexual enhancement drugs; engaging in unprotected anal intercourse with non-regular partners; and use of risk-minimisation strategies as an alternative to condom use.[1,2]

The Down An' Dirty website has been created to assist men to access information about sexual practices, recreational drug use and safety. It allows men to ask questions about sexual health to medical practitioners, and to read the questions from other men who engage in sexually adventurous practices. The site encourages user interactivity through online videos and moderated comments. As such, it has been designed to evolve and adapt to users' needs over time.

There are two men leading the project: Carlos Sepulveda from VAC/GMHC and Wolf Graf from PLWHA Victoria. Both have extensive knowledge of SAM networks in Melbourne such as the Bear, Leather and BDSM (bondage, discipline sadism and masochism) communities. According to Carlos, 'the website is about minimising risk on each and every practice and is a response to the fact that SAM will often use methods of risk reduction other than condoms. SAM are generally more susceptible to STIs as a result of this and having multiple partners.'

Carlos explains that it has been a lengthy process getting Down An' Dirty up and running. Gathering information from SAM was the first step. 'This is very different to outreach programs. Organisations are not telling guys what they need but rather, asking what they want from us. SAM are steering the project, not us.' Down An' Dirty involves key players from the gay community as well as SAM who are active in the scene. Carlos and Wolf have liaised with venue owners, sex party organisers and various interest groups such as VicBears, Mega-Fist and Melbourne leather groups. Retailers such as Manhaus, Lucrezia & DeSade and Eagle Leather have also provided feedback. 'It's important to have a good relationship with stakeholders in the community,' Carlos says. 'We're constantly drawing information from these groups.'

Down An' Dirty: Overview

The **Sexual Practices** section of the website provides a thorough overview of the different practices engaged by SAM. These include BDSM, fisting, watersports and anal play as well as more obscure sexual practices.

Information is provided about how to use sex toys such as dildos, butt plugs and vibrators as well as how to clean them properly. There is useful discussion on how to minimise the risk of physical harm and/or STIs such as using gloves, trimming fingernails, washing and disinfecting hands. Other activities popular among SAM such as piercing, tattooing and scarification are also explored in detail. In each example, much attention is given to undertaking these practices in a way that maximises

The Down An' Dirty website has been created to assist men to access information about sexual practices, recreational drug use and safety. It allows men to ask questions about sexual health to medical practitioners, and to read the questions from other men who engage in sexually adventurous practices.

pleasure and minimises the risk of physical injury and/or STIs.

Methods for risk reduction other than condom use during anal intercourse are common among SAM and close scrutiny is given to these within the website. These strategies include:

- negotiated safety: where two men agree to have safe sex outside a relationship, limiting unprotected anal intercourse (UAI) to between partners in a regular relationship
- withdrawal prior to ejaculation
- strategic positioning: when the HIV-positive partner takes the receptive position during UAI
- serosorting: choosing to have sex with partners of the same serostatus, and
- undetectable viral load: partners of different serostatus choosing not to use condoms where one partner has an undetectable viral load.

The pros and cons of these strategies are highlighted and strong clarification is given that these methods are by no means a safeguard from STIs, including HIV.

The **Enhanced Fun** section of the site provides information about a variety of recreational and sexual enhancement drugs, detailing each the effect of each drug, their potential long-term physical and psychological impacts and possible consequences of mixing various substances. Importantly, the section warns that any drug-taking prior to sex can lower inhibitions and impair decision-making processes, thus leading to a greater risk of physical harm and/or STIs.

Multiple links on both pages also refer the reader to current VAC/GMHC sexual health campaigns such as 'Wherever Sex Happens' and 'The Drama Down Under' which provide detailed information about STIs and proper condom use as well and other essential information. There is also a **Useful Links** page which provides access to a variety of relevant websites such as GLBTI counselling services, drug and alcohol services, fetish groups, bars, clubs and sex-on-premises venues (SOPVs).

The **Ask A Specialist** section gives readers the opportunity to post questions regarding sexual health and sexual practices. The questions are then directed to the most

appropriate channels ie: a sexual health clinician, VAC staff member or someone who is experienced in that particular sex practice.

A major feature of the site is the **Video Section** which allows members of the SAM community to upload their own video content. There are currently five videos online, four of which were produced in conjunction with VAC/GMHC/PLWHA. These films were produced in the men's private settings and offer intimate accounts of their personal lives, sex lives and relationships. Viewers are also given space to comment on the films.

Feedback from site users

Vincent has explored group sex and multiple partners but his favourite activity is watersports or 'playing with piss.' He attends watersports parties at venues such as Club 80 in Melbourne and private garages. Vincent finds the Down An' Dirty website very instructive. He says it provides a lot of information and it's easy to navigate. He says it needs on-going review though. 'They've gotta get people used to interacting with it – push the fact that it's an interactive resource.'

Alex mostly hangs out in the gay male Leather scene. He gets into flogging, corporal punishment, fisting, watersports and breathplay. 'I've got a Master, I'm in a Leather family and I train Submissives.' Alex loves the lifestyle and aesthetic of the Leather scene. 'It's hot to look at but it also has a cultural context. It goes back to the post WWII military era and the bikers in the fifties. Leather etiquette is steeped in military protocol,' he says.

Alex only engages in SAM practices with people he trusts and says that it turns him on sexually and helps him unwind. Alex thinks Down An' Dirty is a great resource, describing it as 'really detailed, the safe sex input is good. He says that it could be updated to embrace transmen and others in

> The Enhanced Fun section of the site provides information about a variety of recreational and sexual enhancement drugs, detailing each the effect of each drug, their potential long-term physical and psychological impacts and possible consequences of mixing various substances. Importantly, the section warns that any drug-taking prior to sex can lower inhibitions and impair decision-making processes, thus leading to a greater risk of physical harm and/or STIs.

the broader kink community though. 'Leather women have a lot to offer too. This could make it more diverse and promote more online discussion.' Alex also enjoys learning about the more obscure practices on the site.

Duke is into fisting and arse play. Duke has his own play room at home with a sling in the shed as well as a digital projector and sound system for porn. A mixture of gay guys and closeted guys come to his place. 'We have threesomes on a regular basis but sometimes up to six guys will attend. My sex partners become mates.' Duke says that some guys don't know much about sexual etiquette though. *The Ethical Slut* is a book that talks a lot about this – it's a must for all SAM.'

Duke is impressed with Down An' Dirty. 'It's very comprehensive and helpful and well laid out. I particularly like the question and answer section.' He recommends having some specific books earmarked in the Sex Practices link and says that the Question & Answers could be used to market the site further. 'GPs can't answer everything because they're not on the scene,' he says.

Moderating the site

According to Carlos Sepulveda, there is a need to moderate feedback on the site to avoid abusive posts. For example, one video tells the story of a couple in an open but committed relationship. 'A disgruntled reader posted some rude comments about the status of their relationship and I felt I had to respond. The guys on the videos have been great to share their personal stories and I won't have them berated by strangers.' Carlos says that feedback needs to be monitored and approved because there are lots of egos, strong opinions and strong personalities among SAM.

The SAM project recently held three focus groups with sexually adventurous men at VAC/GMHC in November 2011 and will conduct more in 2012. According to Carlos, the participants agreed that the visual elements of the website engaged their attention and encouraged them to explore it further. Also, as the website is produced by VAC/GMHC and PLWHA, and their logos are displayed throughout, participants immediately assumed that the website had an HIV prevention purpose.

'There was an extremely favourable response to the videos,' Carlos says. 'Participants found them interesting, thought-provoking and engaging and frequently commented on the diversity of the men profiled and the diversity of sexual practices addressed.' They also commented favourably on how the videos cover a broad range of issues related to sex and relationships. 'The videos were described as making HIV prevention 'more real', even if they do not always explicitly talk about safe sex,' Carlos says.

Summary

The men I spoke to for this article were, overall, very impressed with Down An' Dirty. While they did express the need for ongoing review, they were more than satisfied with the information and resources provided and the ease of navigation. Minor improvements were suggested, such as the provision of books and the need to market the website more proactively – possibly expanding the breadth of information to include other members of the GLBTI community such as transmen. Ultimately, the SAM community needs to be encouraged to interact with the resource, if the website is to keep thriving.

References

1   Hurley, M., Prestage, G. (2007). Intensive sex partying: contextual aspects of 'sexual dysfunction'. *Journal of HIV Therapy* 12(2), 1–5.

2   Smith, G., Worth, H., Kippax, S. (2004). *Sexual adventurism among Sydney gay men*. Monograph 3/2004. National Centre in HIV Social Research (NCHSR). NCHSR, Sydney. Retrieved from: http://nchsr.arts.unsw.edu.au/media/File/Sexual_adventurism.pdf

James May is a freelance writer in Melbourne and regularly contributes work to the HIV sector in Victoria. He has also written for various magazines including *MCV*, *Positive Living* and *HIV Australia*.

… the participants agreed that the visual elements of the website engaged their attention and encouraged them to explore it further. Also, as the website is produced by VAC/GMHC and PLWHA, and their logos are displayed throughout, participants immediately assumed that the website had an HIV prevention purpose.

REGIONAL FEATURE: FORGOTTEN VOICES: LISTENING TO HIV-NEGATIVE PARTNERS IN SERODISCORDANT RELATIONSHIPS IN VIETNAM

By Sally Cameron

In 2009, UNAIDS estimated that more than 90% of the 1.7 million women living with HIV in Asia had been infected by their husbands or partners while in long-term relationships. Women are frequently infected by men who engage in high-risk sexual behaviours including unprotected sex between men, unprotected commercial sex, and sharing of contaminated injecting equipment.

Across Asia, most men engaging in high risk behaviours either are married or will marry. Domestic epidemics are changing as HIV infection risk is no longer isolated among small population groups engaging in high risk activities; infection rates among women reflect this change. In 1990, women comprised 17% of all adult HIV infections in Asia. By 2008, that rate had doubled to 35%. Today, an estimated 50 million women in Asia are at risk of HIV infection from their intimate partners.[1]

This pattern is reflected in Vietnam. Historically, most HIV transmission in Vietnam has been among men but data shows that women are increasingly at risk (see Figure 1).

HIV prevention efforts to address this trend face enormous challenges because they strike at the root of social norms and gender inequalities. There are social and religious taboos and often legal penalties associated with high risk behaviours; social pressure to marry (requiring suppression of sexualities); social acceptance of men's premarital and extramarital heterosexual sex; expectations of women's 'innocence' in sexual matters; women's responsibility for contraception without power to negotiate safe sex; domestic violence; and short-term economic migration, sometimes to regions of high HIV prevalence.

Increasingly, state and community actors are recognising that HIV transmission in intimate partner relationships require a sophisticated response, including more than a focus on the mechanics of prevention. This article outlines some of the innovative work being conducted in Vietnam to shed light on the experiences of HIV-negative partners in serodiscordant relationships.

Positive Voices – Vietnam

The Community Advocacy Initiative (CAI) is a partnership program that aims to strengthen community sector HIV advocacy capacity. CAI in Vietnam is funded by AusAID[3], with AFAO and APCASO as project partners.

A 2009 Vietnamese study[4] found serodiscordant relationships were not uncommon, with almost half of the 1,300 HIV-positive men interviewed living with an HIV-negative partner. In October 2011, Vietnam's CAI country partner, the Center for Supporting Community Development Initiatives, hosted a national workshop on 'Forgotten Voices: The Issues of Negative Partners of PLHIV and Sero-Discordant Couples'. The workshop aimed to highlight issues experienced by HIV-negative partners so that they might better inform the country's national HIV and AIDS response. The workshop also provided a space for dialogue between advocates for, and networks of, negative partners and key government and development agencies in Vietnam. The workshop was attended by representatives of groups of negative partners from all over Vietnam, UNAIDS, WHO, Vietnam's Vice-Health Minister and members of the media. Following the meeting, the Vice-Health Minister expressed his support for initiatives that help address the needs of HIV-negative partners.

This article aims to promote the voices of negative partners of people living with HIV (PLHIV) in serodiscordant couples heard at that workshop, including their experiences reported in the 2010 survey on the sexual and reproductive health of HIV-negative partners of sero-discordant couples (the CSCDI[5] report).

The CSCDI report reinforces analysis of surveillance data that HIV-negative partners are frequently women. In that survey, women comprised 88% of the HIV-negative partners among 307 serodiscordant couples. The data contained below has not been disaggregated by gender so it includes responses from both men and women.

Disclosure

Notably, only 18% of respondents in the CSDI report had been informed of their partner's HIV status before making the decision to commit to the relationship. The survey revealed many barriers to disclosure including fear of being stigmatised, isolated or abandoned; fear that confidentiality would be breached; and concern that a partner would refuse sex. Decisions not to disclose or to delay disclosure were not straightforward and often involved considerable anxiety and guilt:

'He is suffering a lot. He's miserable because he loves her too much. He is so afraid of losing her. Last time he lost a
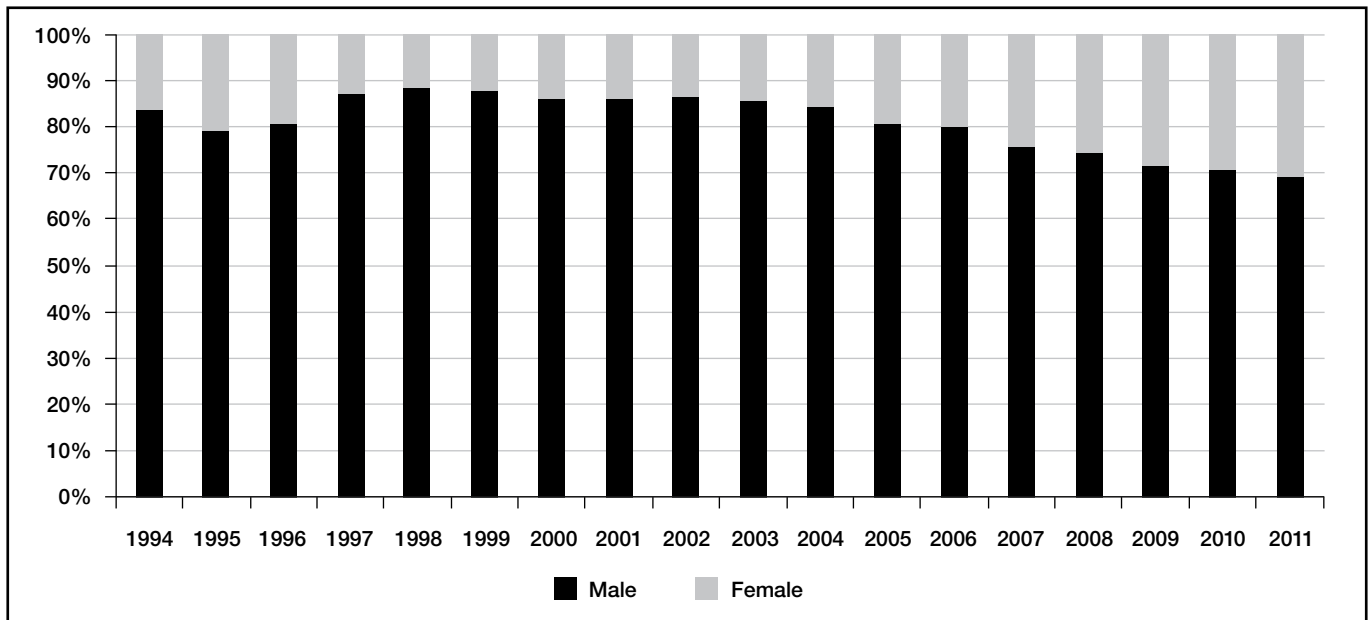
Figure 1 Vietnam HIV case reports 1994–2011[2]

girl just like that, so now he is so afraid of losing this girl. We are all worried about him. One thing that makes it worse was that they didn't use a condom. He wanted to use one but she was upset. She said to him, "Do you only want to use me? Why do we need to use a condom? Do you want to avoid taking responsibility?". We keep telling him "you should tell her"' but he hasn't been able to. We don't know what to do. Poor guy.'

Some had given up relationships rather than disclose:

'That girl is really sweet. I like her a lot but it's over now ... because I didn't know how to tell her. I wanted to but I didn't know how she would react. I am afraid that she would look at me differently. And she could go tell other people ... So I let go.'

Others had received reassuring responses after disclosing their HIV status to intimate partners:

'Well, it was normal, because she had come back from school (at a drug centre) so she was used to hearing about HIV'.

And

'Because we're so in love ... Yeah, when you are in love, you have no fear.' (Male.)

Complexity of relationships

The survey found a range of factors informing HIV-negative partners' experience of their serodiscordant intimate relationships. For the
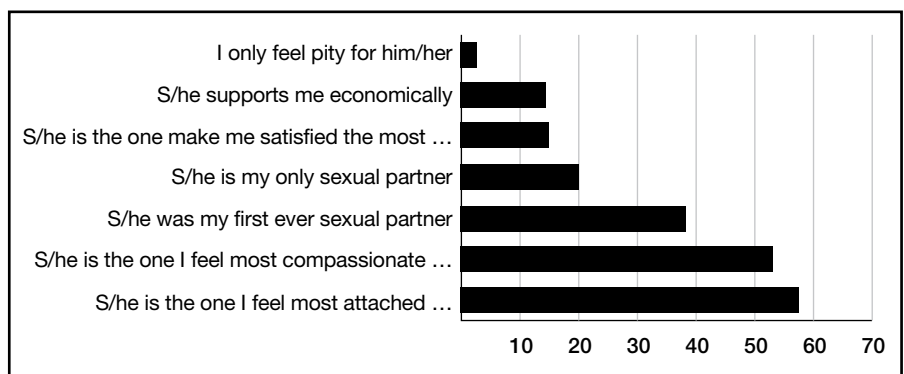

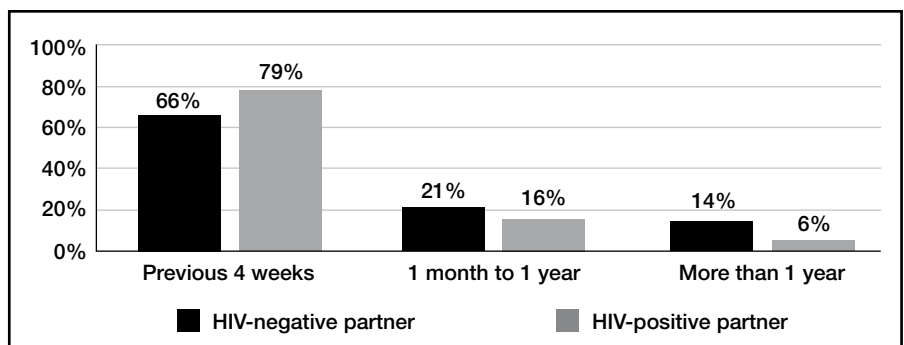**Figure 2** Relationship factors reported by serodiscordant couples[6]

Figure 3 Interval since last occurrence of sex[7]

majority, romantic attachment was the primary reason for choosing to be in a relationship, out weighing HIV-related concerns (see Figure 2). However, as Figure 3 illustrates, for many couples fears about acquiring HIV had a dramatic impact on maintaining a pleasurable sexual life.

Condom use

In Vietnam, women are widely perceived as being responsible for contraception (it's 'women's business') but social mores mean they are often unable to negotiate effectively on reproductive issues. Many married women consider infidelity by their husbands to be common, but they rarely used condoms.

Condom use also remains low amongst serodiscordant couples; however, there is some evidence that health promotion

initiatives are having an effect and condom use is increasing among serodiscordant couples.

Of those surveyed who had had sex in the previous four weeks[8]:

■ 12% reported inconsistent condom use
■ 13% reported no condom use
■ 8% had never used a condom in their life.

Condoms had become an integral part of sex for some, as the following quotes illustrate:

'At the beginning, it felt strange but as we use it all the time, it becomes normal. Now we use it all the time.'

'Well, I am afraid that my wife will get pregnant then she would become weaker. And she is afraid of infecting me.'

Many couples in serodiscordant relationships also described fears about acquiring HIV and difficulties maintaining a sexual relationship, even when using condoms:

'Sometimes while we are doing (sex), I stop and check the condom. I am so afraid.'

'We have our own beds … I have a "body guard" so I am not afraid … our son (who sleeps with the father). When he goes to sleep, he uses a scarf to tie his wrist to his dad's and tell him, "Don't you go anywhere"'. (Female.)

For others, condom use remained a burden or was incompatible with their priorities:

'I recognise that every time we use condoms, [my husband] *does not enjoy it. He used condoms because he was afraid of infecting me but he doesn't like it. I love him very much. I don't want to lose him. I'm afraid that he may go and look for a woman with HIV to have sex with. And me too. I don't like condoms. We both enjoy sex so much every time we decide not to use condoms. So, I have to admit to you that we have stopped using condom.'*

Having children

The interface between HIV prevention and family planning strategies remains underdeveloped. There is a large unmet need for information on minimising HIV transmission risk while trying to get pregnant.

Of those surveyed, 75% had children, 75% had been pregnant to their positive partner, and 24% wanted to have/to have more children. A number of factors influenced respondents' desire to have or have more children, including:

■ compassion/responsibility to family
■ wanting to contribute to family ancestry
■ wanting to show commitment and love
■ feeling encouraged after having one child 'safely'
■ being inspired by others who have children safely.

Many respondents had struggled to manage their HIV infection risk and their (and/or their families') desire to have children:

'At the beginning we used condoms. Then I heard his Mum say, 'This family is so unfortunate. Every other family has grandchildren except this one'. So I stopped using condoms. I made that decision on my own. I stopped for three months then I got pregnant.'

Numerous word of mouth 'risk reduction' methods had been used. Survey respondents reported strategies including:

■ 'We cut the tip of the condom'
■ 'We calculated the days and didn't use condoms on those days'
■ 'We calculated the days then he masturbated and only put in his penis when he was about to ejaculate'
■ 'We had sex without a condom then took ARV medication'
■ 'We had [sex] very gently [without a condom]'.

Conversely, 17% of those who had become pregnant to an HIV-positive partner reported the pregnancy was due to lack of access to a contraceptive that suited their needs.

Community advocacy and support

For the past two years Bright Futures, a community-based organisation governed by people living with HIV, has been running a peer-support group for the partners of HIV-positive people. The group, operating out of Hanoi, has created a much needed space in the community for the negative partners of HIV-positive people to talk and learn from each other and has been instrumental in breaking down the isolation that many partners of HIV-positive people feel. As one participant explains:

'The biggest change is that we now have a chance to get together to talk. Before the group we were isolated. We can't talk about these things with neighbours. The group gives us a chance. It's our group.' [9]

HIV programs must be responsive to the experiences of people living with and affected by HIV if they are to be effective. AFAO/APCASO will continue to strengthen advocacy capacity among community-based organisations such as Bright Futures to ensure that new community-led initiatives can flourish and grassroots voices continue to be heard.

References

1   UNAIDS. (2009). *HIV Transmission in Intimate Partner Relationships in Asia.* Geneva.
2   National Committee for AIDS, Drugs and Prostitution Prevention and Control. (2012). *Vietnam AIDS Response Progress Report Hanoi,* March 2012.
3   Through the HIV Consortium for Partnerships in Asia and the Pacific.
4   Conducted by the Institute for Social Development Studies and the Vietnam Civil Society Partnership Platform on AIDS.
5   A report produced by the The Center for Supporting Community Development Initiatives (CSCDI) Community Advocacy Initiatives Project Vietnam.
6   Fontaine, C. (2011). HIV transmission in intimate partner relationships. CAI presentation, UNAIDS, Viet Nam.
7   ibid.
8   ibid.
9   Interview with Bright Futures support group participant, 26 October 2011.

Sally Cameron is a consultant for AFAO.

UNPLANNED TREATMENT INTERRUPTIONS INVOLVE A GREATER RISK OF VIROLOGICAL FAILURE THAN MISSING OCCASIONAL DOSES

Unstructured treatment interruptions – rather than missed doses of medication – involve a greater risk of a detectable viral load, US research published in the online edition of *AIDS* suggests

Investigators analysed the results of 16 clinical trials, using the Medication Event Monitoring System (MEMS) to monitor treatment compliance and to see which pattern of non-adherence had the greatest effect on viral load. 'Patterns of adherence have different impact on the risk of detectable HIV,' comment the authors. 'Missing days of medication consecutively may have a greater impact on being detectable than missing the same amount of time in a non-consecutive manner.'

Adherence is the most important factor affecting the virological success of HIV therapy. The best results are seen in patients who take all or nearly all their doses of medication correctly and patients are encouraged to aim for near-perfect levels of adherence. Newer, more potent antiretrovirals appear to be more forgiving and seem to remain effective at somewhat lower levels of adherence. However, it is unknown if particular patterns of non-adherence are associated with a greater risk of lack of viral suppression.

MEMS electronically records the opening of medication containers and is a useful tool for assessing patient adherence to therapy. The system is able to identify both individual missed doses and longer treatment interruptions.

Treatment interruptions were associated with an even greater risk of viral load being detectable. The risk increased with the duration of the interruption and was highest for patients who stopped taking their treatment for 21 days or longer (OR=3.65; 95% CI, 2.77–4.81). However, an interruption of between 7 and 14 days was associated with a doubling of the risk of a detectable viral load (OR=2.06; 95% CI, 1.58-2.68).

'In this study there was a clear dose-relationship with each increasing week of interrupted time … the risk was statistically significant starting at interruptions between 7 and 14 days,' observe the authors. 'This does not suggest that shorter interruptions are safe. Our data does not suggest a tolerable lower bound.'

Occasional missed doses were more likely to lead to viral load becoming detectable for people taking a regimen based on an NNRTI than for those treated with a combination containing a boosted protease inhibitor.

'Future research should focus on individual, interpersonal, and structural determinants of consecutive missed doses and the evaluation of interventions designed to improve adherence,' suggest the authors. 'Patient provider communication should focus on patterns of medication-taking and work towards shortening and eliminating interruptions in treatment.'

Reference

Genberg, L., et al. (2012). Patterns of ART adherence and impact on HIV RNA among patients from the MACH14 study. *AIDS*, online edition. DOI: 10.1097/QAD.0b013e328354bed6, 2012.

— **Michael Carter (aidsmap.com)**
Published: 4 May 2012

COGNITIVE FUNCTION IMPROVES THROUGH THE FIRST YEAR OF HIV THERAPY

Cognitive function continues to improve up to one year after starting antiretroviral therapy, according to the results of a small international study published in *HIV Medicine*.

The investigators monitored changes in cognitive function six and twelve months after patients started therapy. Significant overall improvements were observed at both time points. Changes in cognitive function varied according to treatment regimen and improvements were less pronounced in patients taking a regimen based on efavirenz (*Sustiva*, also in *Atripla*) than those seen in people taking alternative regimens.

'Overall, and of clinical relevance, we observed improvements in neuro-cognitive function in neuro-asymptomatic HIV-infected subjects commencing antiretroviral therapy for the first time,' write the authors. 'The majority of improvements were present within 24 weeks of commencing therapy and continued improvements were observed until 48 weeks after starting therapy.'

It is well-recognised that starting HIV treatment can lead to improvements in neuro-cognitive function. However, few studies have explored the timing or dynamics of cognitive changes in people starting antiretroviral treatment.

Investigators from the ALTAIR study therefore designed a sub-study involving 28 patients. All these people were starting HIV therapy for the first time and none had symptomatic cognitive dysfunction.

The investigators suggest this finding could be due to 'a specific effect of efavirenz … acute neuropsychiatric disorders are well described with efavirenz use and may persist with extended therapy.'

Significant improvements in executive function were not seen until week 48, and then only in the AZT/abacavir-treated patients (p=0.02).

'Improvements in neuro-cognitive function in individuals commencing combination antiretroviral therapy for the first time may be related to control

of HIV viraemia and/or recovery of cerebral synaptodendritic injury,' comment the authors.

They believe their findings 'may assist in the design and development of future treatment and research programmes assessing changes in cerebral function over time in HIV infected subjects'.

Reference

Winston, A., et al. (2012). Dynamics of cognitive change in HIV-infected individuals commencing three different initial antiretroviral regimens: a randomized, controlled study. *HIV Med 13*, 245–251.

— **Michael Carter (aidsmap.com)**
Published: 29 March 2012

NICE SAYS SPERM WASHING IS NO SAFER THAN EFFECTIVE TREATMENT AND TIMED INTERCOURSE

Draft UK guidance on fertility treatment says that sperm washing may no longer be necessary for couples where the man has HIV and the woman does not. As long as the man is on effective antiretroviral treatment and unprotected sex is limited to days when his partner is ovulating, 'sperm washing may not further reduce the risk of infection.' On the other hand, the guidance does not support the use of pre-exposure prophylaxis (PrEP) by the HIV-negative partner.

The National Institute for Health and Clinical Excellence (NICE) is an influential body which issues recommendations to the NHS about the most effective and cost-effective treatments to provide. Their draft guidance on fertility treatments – an update to a document previously issued in 2004 – was issued today and is open for consultation.

As in the previous version, people with HIV are not excluded from access to fertility treatments, such as intrauterine insemination (IUI) or in vitro fertilisation (IVF). Moreover, the authors have removed a previous recommendation that the implications of the parent's HIV infection for

the child's welfare 'should be taken into account'.

The writing group reviewed in detail the scientific evidence for different methods that a couple could use to become pregnant, where the man has HIV and the woman does not. Previous guidance recommended sperm washing, but the experts also looked at the evidence for effective antiretroviral treatment and for pre-exposure prophylaxis.

'The evidence showed that whilst sperm washing did not appear to completely eliminate the virus in the semen on the basis of post-wash testing of prepared semen, the procedure appears to be very effective in reducing viral transmission in that no cases of seroconversion of the woman or the baby has been documented,' they found. On the other hand, sperm washing has the disadvantage of reducing the likelihood of pregnancy occurring.

Moreover, the writing group identified effective HIV treatment as an alternative 'which is equally effective, less invasive and more cost effective'.

They propose criteria, similar to that of the 'Swiss Statement', to determine whether unprotected vaginal intercourse would be an appropriate way to conceive. All the following conditions should be met:

- Unprotected intercourse is limited to the time of ovulation.
- The man is complying with highly active antiretroviral therapy (HAART).
- The man has a plasma viral load of less than 50 copies/ml.
- There are no other sexually transmitted infections.

Consultation is open until 3 July 2012.

— **Roger Pebody (aidsmap.com)**
Published: 22 May 2012

UNTREATED HIV INFECTION IS ASSOCIATED WITH HIGHER BLOOD ALCOHOL LEVELS

Starting HIV treatment is associated with reductions in blood alcohol levels, results of a small pilot study published in the online edition of the *Journal of*

Acquired Immune Deficiency Syndromes suggest. The investigators believe this could be related to 'inflammatory responses to untreated HIV infection' in gut tissue, which could produce 'greater likelihood of alcohol-related toxicities.'

A number of studies have already shown that alcohol abuse is related to faster HIV disease progression, however, the effect of HIV on alcohol metabolism and responses has received little attention. It is also unclear if the body's response to alcohol is affected by starting antiretroviral therapy. Investigators in San Francisco therefore designed a small trial involving 15 HIV-positive patients.

'This is the first study, to our knowledge, that demonstrates a significant difference in blood alcohol concentrations in individuals with HIV/AIDS prior to and following initiation and stabilization of ART (antiretroviral therapy),' write the authors. 'These effects were the result of treating the HIV infection, rather than being direct pharmacokinetic drug interactions.'

They believe their findings 'support other investigations indicating that HIV infection is associated with damage to intestinal epithelium.' The investigators hypothesise that HIV replication in the lining of the gut could cause a decrease in alcohol metabolism in the gut and therefore greater absorption of alcohol.

If supported by larger study, then the findings of the current research could have implications for HIV treatment and care strategies. The investigators conclude: 'These results support the rationale for the early detection and treatment of hazardous alcohol use and alcohol use disorders, as well as earlier or universal ART in untreated HIV-infected populations.'

Reference

McCance-Katz, E., et al. Untreated HIV infection is associated with higher blood alcohol levels. J Acquir Immune Defic Syndr, online edition. DOI: 10.1097/QAI.0b013e318256625f, 2012.

— **Michael Carter (aidsmap.com)**
Published: 25 April 2012

● Subscribe to *HIV Australia*

If you're not already receiving a copy of *HIV Australia* but would like to, please complete your details below and return to *HIV Australia*, PO Box 51, Newtown NSW 2042 Australia or fax to (+61 2) 9557 9867

Name	
Organisation	
Address	
Country	
Email	
Telephone	

Diary

● July

19–20
7th International Workshop on HIV Transmission – Principles of Intervention
Washington DC, US
http://www.virology-education.com

19–20
LIVING 2012: the 13th International Conference of People Living With HIV
Washington DC, US
http://www.gnpplus.net/es/noticias/1740-people-living-with-hiv-conference-living2012-to-be-held-in-washington-dc

19–21
14th International Workshop on Adverse Drug Reactions and Co-morbidities in HIV
http://www.intmedpress.com/comorbidities

20–21
Global Scientific Strategy towards an HIV Cure (working group, preceeding AIDS 2012)
Washington DC, United States
http://www.aids2012.org

21
MSM Pre-Conference to the XIX International AIDS Conference
Washington DC, United States
www.msmgf.org/index.cfm/id/266/Home

22–27
AIDS 2012 – XIX International AIDS Conference
Washington DC, United States
http://www.aids2012.org

July 30–August 1
BIT's 2nd Annual World Congress of Microbes – 2012 (WCM-2012)
(Incorporating the 3rd Annual Symposia of HIV (HIV-2012)
Dalian, China
http://www.bitlifesciences.com/wcm2012/default.asp

● August

18–22
The 30th World Congress of Biomedical Laboratory Science
Berlin, Germany
www.ifbls-dvta2012.com

● September

9–12
AIDS Vaccine 2012
Boston, USA
www.hivvaccineenterprise.org/conference/2012

● October

15–17
13th International Union against Sexually Transmitted Infections (IUSTI) World Congress
Melbourne, Australia
http://www.iusti2012.com

17–19
Australasian HIV/AIDS Conference 2012 (24th Annual Conference of the Australasian Society for HIV Medicine)
Melbourne, Australia
http://www.hivaidsconference.com.au

● November

5–6
3rd International Workshop on HIV and Aging
Baltimore, USA
http://www.virology-education.com

11–15
Eleventh International Congress on Drug Therapy in HIV Infection
Glasgow, UK
http://www.hiv11.com

If you're living with HIV then talk to your doctor. Early treatment can have important health benefits and can protect your partners. Don't put off treatment any longer and learn about the latest developments.

napwa.org.au

napwa national association of people living with HIV/AIDS

START THE CONVERSATION TODAY