

HIV AUSTRALIA

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**Keeping community
at the centre of HIV research**

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

AFAO's aims are to:

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

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This edition of *HIV Australia* explores the key role of people with HIV and affected communities in driving Australia's HIV research agenda, and in the development and evaluation of innovative and effective HIV education campaigns.

Contributors look at peer-based approaches informing HIV research, evaluation and health promotion processes, and highlight how community-research partnerships have underpinned Australia's response to HIV since the very beginning.

The edition also reflects on AFAO's 30-year history of HIV health promotion work. Following a competitive tender process, this long-running program came to a close in June 2016. *HIV Australia* acknowledges the hard work of all the staff involved, and pays tribute to the nine AFAO staff who left the organisation this year due to the funding restructure, including one of the editors of *HIV Australia*, Linda Forbes.

***HIV Australia* online includes additional content not published in the printed edition.
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To submit an article or report for consideration, email editor@afao.org.au



Discovering, empowering, and innovating: 30 years of HIV research, working in partnership with the community

By **The Kirby Institute**

For three decades, the Australian response to HIV has been marked by an enduring phenomenon: cooperation and respect between medical researchers and community. The first ten years of the epidemic were the most difficult, with the constant spectre of illness and death in the absence of effective treatments. The turning point came in 1996, the year in which the treatment revolution transformed HIV from a lethal infection into a manageable condition.

By 2006, medical research had turned its focus both to the best uses of antiretroviral therapy and its role in the prevention of HIV transmission. This long, constructive, ongoing journey began in 1983. Doctors, including the Kirby Institute's David Cooper and Basil Donovan, met with representatives of key gay organisations and together decided to set up a cohort study of gay men in Sydney to monitor what was happening. They held a gay community meeting at Paddington Town

Hall to explain what they were going to do. Hundreds of men came, the Kirby's Garrett Prestage among them.

'We were all scared, and hungry for information, and for some sign that we could do something,' Prestage said. He found the meeting reassuring because doctors and the community were working together.

'They explained what they knew, which wasn't much, and why they needed, no, why we needed, to set up a cohort study,' Prestage continues. 'That study was eventually called SAPS (the Sydney AIDS Prospective Study), and was one of the most influential early studies internationally in the response to HIV.

'It led soon after to the setting up of the National Centre in HIV Epidemiology and Clinical Research (now the Kirby Institute), under David's leadership from the beginning. So, the Kirby's very foundation was based in a direct and strong relationship between researchers and community.'

This long, constructive, ongoing journey began in 1983.

Doctors, including the Kirby Institute's David Cooper and Basil Donovan, met with representatives of key gay organisations and together decided to set up a cohort study of gay men in Sydney to monitor what was happening. They held a gay community meeting at Paddington Town Hall to explain what they were going to do. Hundreds of men came, the Kirby's Garrett Prestage among them.

David Cooper acknowledges the difficulties of the first decade. 'We were faced with explaining the goals of research at a time when we had no treatment,' he said. 'The rigors of research, particularly randomisation and placebo, were needed to develop those treatments. Would we have got to where we are now without randomisation and placebos? Maybe, maybe not.'

People were understandably angry when they or their friends were randomised not to the active treatment arm of a study, but to the placebo arm. As a leading trial investigator at St Vincent's Hospital, Sydney, Cooper was the target of much of this anger. He remained both philosophical and focussed on the necessary scientific outcomes of the trials. He also never deviated from the need to work with the community to achieve meaningful outcomes.

'With the help of the community, we developed mechanisms to allow expanded access,' Cooper said. 'Together we overhauled clinical trials regulation in Australia, and access to unapproved drugs.' Cooper nominated Bill Whittaker, the first executive director of ACON, and Peter McDonald as two centrally important figures of that period. McDonald was chairman, and Whittaker a member, of the review task force whose recommendations of sweeping changes to the clinical trials approval in Australia were accepted in full by Brian Howe, Minister for Health in the Labor government.

The subsequent review by Peter Baume (former Liberal politician, and by the time of the Baume Report in 1991, Professor at the University of NSW) of the evaluation of new drugs led to the introduction of the Special Access Scheme. Under the scheme, people failing their treatment regimens, or who had reached a clinical trial endpoint, could get access to trial drugs while clinical trials of the drug were still underway.

Cooper also pointed to the extensive network of committees and working groups established through the 1980s and '90s as giving the community a strong voice. 'There was an evolution in the community response over the years,' he said. 'The distress and understandable frustration, the angry activism of ACT UP, segued into more consultative ways of working together.'

'Reforming the clinical trials mechanisms and the special access for drugs really heralded a true cooperation where the community input was both valuable and welcome. That was clearly demonstrated in getting improved protocols and better research process.'

Prestage noted how the early SAPS study, mentioned above, provided a crucial international piece of the HIV puzzle.

'This was the study that first identified the phenomenon of the seroconversion illness which has become a key tool for diagnosis internationally,' he said. 'And SAPS contributed to the early international understandings of clinical progression that were fundamental to the subsequent development of treatments.'

Prestage sees SAPS as setting the precedent for all of the Kirby's work, and for the entire Australian HIV research response, in ensuring that research was seen as a partnership between researchers, clinicians, affected communities, and infected people. 'It meant that the community didn't just have a role to play, but was committed to the work of the researchers, while researchers had a direct interest in the well-being and best interests of the communities they worked with.'

The role of the National Centre, and particularly Cooper, in the international research effort that led to highly-active antiretroviral therapy (HAART) and its announcement in 1996, is sometimes overwhelmed in the long list of the National Centre's achievements.

'The impact this had on the gay community, especially in Sydney, was utterly fundamental,' Prestage said. 'A community that was unendingly traumatised by constant illness and death, and its apparent inevitability, was suddenly presented with new hope. People speak of the "Lazarus effect", but among gay men that was a very real thing.'

The role of the National Centre, and particularly Cooper, in the international research effort that led to highly-active antiretroviral therapy (HAART) and its announcement in 1996, is sometimes overwhelmed in the long list of the National Centre's achievements. 'The impact this had on the gay community, especially in Sydney, was utterly fundamental,' Prestage said. 'A community that was unendingly traumatised by constant illness and death, and its apparent inevitability, was suddenly presented with new hope.'

The death notices disappeared from the gay press and everyone had friends who were brought back from the precipice. 'From this distance of 20 years, it's hard to keep the enormity of that shift real, and to give people an understanding of what it meant; but this, more than any other achievement in the past 30 years, has had the most profound effect on the gay community,' Prestage said.

The Kirby Institute and its predecessor the National Centre has collaborated widely over 30 years, with large institutes and small sexual health clinics, nationally and internationally, on almost every continent and at every level of engagement. In Australia, crucial collaborations existed with the other two National Centres of HIV Research. All three centres were established in 1986 by the Minister for Health, Neal Blewett, in a politically bipartisan response to the dawning HIV threat. None of the three still carries its original name, and the work of each has broadened.

The collaboration with the National Centre in HIV Social Research – now the Centre for Social Research in Health – gave rise to the Gay Community Periodic Surveys, the most longstanding and effective behavioural surveillance activity among gay men in the world, which marks 20 years in 2016. Prestage argues that in terms of impact on the community, the Periodic Surveys have been a key component to the ongoing commitment to partnership between community and research.

'Here is research that's effectively administered by the community itself, under the supervision of the researchers, and where the research findings are carefully assessed and interpreted by the researchers and community partners together,' Prestage said. 'We all tend to take it for granted now, but there is

nowhere else in the world that does this kind of work, and has so successfully made partnership so practically real.'

Prestage also highlighted the importance of the Seroconversion Study, which ran from 1992 to 2015.

'Throughout the past 23 years, this study has loomed in the background of all of our work, always reminding us, through the voices of those recently infected, of what it means to be affected by HIV and why our work matters.'

The interviews were about fear: the fear of infection that had permeated the men's lives prior to their diagnosis, and the fear of the future given the particularly bleak outlook at the time. In the post-HAART era, the Seroconversion Study has continued to give voice to men who have become HIV-positive.

'The interviews now tell us about the tensions between their fears and their hopes, between their vulnerabilities and their strengths, and between their personal traumas in dealing with the process of diagnosis and disclosure and their collective journey in finding their

place in the community with support from their peers,' Prestage said. 'So, for me, the Seroconversion Study has been the constant voice in our ear as we work. It's the way we know that what we do matters. And when the guys who are interviewed almost universally thank us for the opportunity to tell their story, so it can help inform others, and they've been saying it for over 20 years, then I know that it's very special.'

The Kirby's partnerships with community continue. The most recent example is the launch of EPIC-NSW (Expanded PrEP Implementation in Communities in NSW), at Mardi Gras in 2016. EPIC-NSW, following 2015's Prelude demonstration study at eight sites, combines rapid roll-out with population-level monitoring, with the target of reaching 3,700 high-risk men through sexual health clinics and specialist GPs.

'This trial presents an exciting opportunity to dramatically reduce HIV diagnoses in New South Wales,' Cooper said. 'Rapid enrolment, high coverage and precision targeting are crucial to the success of this trial, which has the potential to virtually eliminate new HIV infections by 2020.'

'New South Wales Health has committed crucial resources for this trial and has drawn together key partners. We're excited to be working again with ACON, Positive Life NSW and ASHM (Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine). It's this partnership approach that is the principal strength of this trial.'

The Kirby Institute is a leading global research institute dedicated to the prevention and treatment of infectious diseases, with a particular focus on HIV, viral hepatitis and sexually transmissible infections. In 2016, the Kirby Institute celebrates its 30th year.

The Centre for Social Research in Health at UNSW Australia is seeking people living with HIV to take part in a 15 minute online survey about experiences of living with HIV, including HIV treatment, sources of social support, your use of substances like alcohol, mental health and wellbeing and your experiences of stigma and discrimination related to HIV.

This study is part of a broader project funded by the Australian Government Department of Health to examine stigma and discrimination among people living with blood borne viruses and sexually transmitted infections.

Have your say on stigma and discrimination

To complete the survey or find out more, visit:

bit.ly/hivstigmaurvey
or contact Elena at e.cama@unsw.edu.au

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Get over the fear and loathing: designing a robust research and evaluation strategy

By **Rigmor Berg**

For many people working in HIV prevention and support, mustering energy and enthusiasm for evaluation is a challenge, to say the least. The processes can be tedious, inconvenient and time consuming. But evaluation is necessary, and not just because funding requires it. It can also be extremely useful when it is done well.

Consider communications. You know what you mean to say and so does everyone in your workplace, but you can only understand how your message is understood by others by testing it with a naïve sample. For some in your audience, the message may be interpreted quite differently from the way you intended. Small changes in graphics or text can greatly affect the way a message is received.

That may be obvious when an ambiguous word or omitted 'not' distorts a crucial message, but there are more subtle examples.

Following market testing, the much loved Sistergirls campaign (developed by Anwernekenhe National HIV/AIDS Alliance [ANA] and the Australian Federation of AIDS Organisations [AFAO] in 2003, reproduced on page 18), was significantly changed by inserting the word 'say' into the central message, 'Sistergirls [^] cover yourself'. This small change had a big impact: it presented the sistergirls themselves as the champions of the message to get condoms onto insertive partners and changed the tone of the campaign from lecturing to empowering.

Another classic example of unintended messaging was picked up in the

evaluation of a pamphlet about men from regional areas visiting the city to find sex. A cartoon depiction of Sydney Tower was mistaken for a church, which added confusing emotional content.

Evaluation should not be an afterthought

Evaluation should be planned from the outset and allowed for in the campaign budget. The initiative itself must have clear objectives and you need to be clear about the purpose and audience for each evaluation component (needs assessment, market testing, impact/outcome or process evaluation). Key questions to consider include:

- Do you need to demonstrate the cost-effectiveness of your initiative to your funder?

- Do you want to show others in the field why your approach is superior?
- Do you want to know which of several approaches can cut through the noise to grab the attention of your target audience?
- Do you want to identify any errors, potential for offending, gaps, misunderstanding or unintended messages in your information resource while you can still change it? Do you want constructive feedback to help you improve your program or attract unresponsive target segments?
- Do you want to know how information needs or motivations vary across your target population?

Your evaluation may be able to serve more than one purpose, but only if you are clear about what you want. Below are a few rules to live by.

Design expertise is essential

The old adage, 'you cannot make a silk purse from a sow's ear' holds true. It is best to get an expert to design your evaluation strategy and data collection instruments. There is real value in using an independent person for data collection and analysis as well, but stuff-ups in design are the most damaging. My worst experiences as an evaluation consultant have been when small organisations have tried to save money by doing most of a job themselves and then asked me to create a report from a flawed dataset.

There are ways to keep costs down, but tasks like questionnaire design require skill and you can't fix a bad dataset. You also can't make up for slack recruitment by getting a few friends to make multiple submissions. A dodgy dataset is very obvious to a researcher. Record keeping is boring, but necessary to show your

achievements at evaluation time. Record everything you do at the time. Count bums on seats and get feedback from participants. Don't leave it all to the end!

In uncertain times, skills get lost

If your program is ongoing, then your evaluation strategy must be sustainable. Recently, a well thought out evaluation strategy supported by training for staff fell down after a couple of years due to basic record-keeping skills being lost through downsizing and staff turnover.

Choose your method wisely: a combination approach works best

Thirty years ago, a simple pre- and post-test method could show that a group had learnt a lot from a workshop, because it was easy to demonstrate that most participants knew very little before the workshop and a lot more after – and intended to change their behaviour. Those days are long gone. In an era where many people already have very sophisticated understandings about HIV, and there are range of prevention strategies available, a far more nuanced approach is needed to demonstrate knowledge gains and behaviour change. A 'one-size-fits-all' evaluation is not sufficient. Every method has strengths and weaknesses and the best evaluation designs use a combination of methods and sources.

Quantitative vs qualitative

Quantitative methods ask closed questions to produce numbers for statistical analysis (e.g., a multiple choice questionnaire). These are efficient for large samples and collect comparable responses that allow you to show change over time, distribution of a belief or behaviour across a population and relationships between

variables. 'Bean counters' tend to like quantitative methods because they appear more objective, producing 'hard' data; they can show something simple with a high degree of certainty. However, quantitative methods are insensitive and inflexible, producing shallow understanding. They depend on having prior knowledge of issues and the range of possibilities and the skills to design a good data collection instrument (questionnaire). The saying 'garbage in, garbage out' was coined in relation to quantitative analysis, though no method has a monopoly on producing garbage. Unbalanced or leading questions, ambiguous or double-barrelled questions, inadequate range in response options and failure to include important issues are common problems.

Qualitative methods ask open-ended questions, producing words (e.g., focus groups or interviews). Qualitative methods are more subjective, producing 'soft' data. They are labour-intensive, so samples tend to be smaller and individual responses may not cover exactly the same territory. However, qualitative methods are much more sensitive than quantitative ones and can provide deeper, more nuanced understanding of human attitudes, experiences and choices. Unanticipated issues emerge because the questions are open and these can be explored because the processes are interactive. This approach can go beyond prevalence of attitudes or practices to reveal underlying causes.

At the time when 'shared responsibility' was a central campaign theme, a quantitative survey would have shown general support for this concept, but focus group discussions commissioned by Queensland Association for Healthy Communities (QAHC) revealed this agreement in theory masked quite different understandings of 'shared responsibility' in practice. HIV-negative men accepted a share of responsibility, but some felt that HIV-positive men had an absolute responsibility to protect others, knowing they were positive. HIV-positive men accepted a share of responsibility, but some felt that HIV-negative men had an absolute responsibility to protect themselves, knowing that they were negative. This led to different assumptions about HIV status when nothing was said and no-one produced a condom in fast sex contexts.

Qualitative research is skilled work and best done by independent specialists.

Thirty years ago, a simple pre- and post-test method could show that a group had learnt a lot from a workshop, because it was easy to demonstrate that most participants knew very little before the workshop and a lot more after – and intended to change their behaviour. Those days are long gone.

Common problems include asking closed or leading questions, failing to actively listen, check understanding and follow up new material, temptation to lecture, plus the facilitator being too closely associated with the initiative for research participants to give frank feedback.

Sampling

Poor sampling is a problem for qualitative methods and quantitative methods alike. It is crucial to remember that there is great diversity in every population, whether men who have sex with men, sex workers, people who use injecting drugs, people with HIV or school kids. They vary in age, gender, geographical location, cultural background, education and literacy, faith, income, relationship status, social milieu, living arrangements, aspirations, fears, past experiences and so forth.

Random samples are extremely rare; most are actually convenience samples. Big polling companies can collect stratified samples that provide proportional representation in relation to a few core variables, but they still contain some bias because telephone survey samples exclude the 30% of the population with no landline at home, while their online survey samples are made up of active volunteers and exclude the 14% of the population with no internet access at home. For most evaluation research, proportional representation is a bar too high. However, we can make efforts to identify key dimensions of diversity and ensure that all segments are included so we can look for differences between them.

Size isn't everything. No matter how numerous or large your samples are, if you repeatedly dip into the same pond (e.g. users of a particular online hook-up app), you can end up knowing a lot about those people, but nothing about members of your target population who are not in that pond.

A lot of focus group recruitment happens at the last minute, but when there is no database of volunteers to select from and no effort is made to recruit from a range of sources, the informants can end up being the project officer, his boyfriend, their housemates and a regular volunteer. These people may have useful things to say, but they are not a good representation of a target population. It is important to reach out further to get responses from people who are not close associates. Some HIV-

relevant populations are harder to access, but none are inaccessible.

It is also important to be mindful of the fact that one person cannot adequately represent a category. Recently I was asked to conduct a single focus group containing one lesbian, gay, bisexual, transgender and intersex (LGBTI) representative, one culturally and linguistically diverse (CALD) representative, one Aboriginal and Torres Strait Islander representative, one representative of residential service users, and so on. This showed some awareness that the target population was diverse, but not sufficient respect for that diversity.

Another consideration is that some people are more confident than others, so in group discussion their perspectives come through more strongly than others. This is partly down to individual personalities, but it is also predictable that in a mixed group, you will hear more from mature, male, Australian-born, non-Indigenous people than from young, female, recently arrived or Aboriginal and/or Torres Strait Islander participants. All relevant perspectives must have a chance to be heard and narrowly recruited groups work better.

Feedback is a gift deserving respect and thanks

While most people love to give their opinion and talk about their own experiences, values and concerns, it is important to acknowledge that this information and feedback is valuable by giving something back. A small incentive payment also helps to attract a less biased sample. I usually give vouchers, but have occasionally given goods or cash. Research participants should not be out of pocket or disadvantaged in any way as a consequence of participating in evaluation research, but

the gesture of reciprocating is probably more important than the actual value of the gift.

Participation in evaluation research should always be voluntary, based on informed consent and confidential, and information gathered should only be used as agreed. It is useful to have a database of people willing to participate in research, but you cannot just add names and contact details without getting explicit consent.

By taking all the above into consideration, you can help ensure that your evaluation produces rich and diverse data, which demonstrates the value of your work and helps to guide future endeavours.

Dr Rigmor Berg BSc(Hons)PhD, Principal of BB Professional Services, has 30 years' experience providing evaluation research services to HIV health promotion clients including National Advisory Committee on AIDS (NACAIDS), AFAO, ACON, Queensland Association for Healthy Communities (QAHc)/Queensland AIDS Council (QuAC), NSW Users and Aids Association (NUAA), Sex Workers Outreach Project (SWOP), Gender Centre, Communicable Diseases Branch of Queensland Health, AIDS Bureau, Drug and Alcohol Directorate and HIV and Related Programs Unit of NSW Health. Contact: rigmor.berg@optusnet.com.au

It is crucial to remember that there is great diversity in every population, whether men who have sex with men, sex workers, people who use injecting drug, people with HIV or school kids. They vary in age, gender, geographical location, cultural background, education and literacy, faith, income, relationship status, social milieu, living arrangements, aspirations, fears, past experiences and so forth.



Because it's thick and sticky: why we need social research to end HIV

By **Darryl O'Donnell**

This is an abridged version of an address given by Darryl O'Donnell at the 2016 Social Research Conference on HIV, Viral Hepatitis and Related Diseases. The speech, delivered on 31 March 2016 at the University of NSW, marked the 25th anniversary of the conference organisers, the Centre for Social Research in Health.

In late 2016, probably November, it is likely that we will face a plebiscite on same-sex marriage. Marriage, for my generation, in my community, can be complicated. It only seems less complicated when I see BuzzFeed images of young gay men cheering on change, and old lesbians standing on US courthouse steps. The plebiscite campaign will be vicious, unprecedentedly so for Australians my age and younger who didn't directly feel the opprobrium of the early years of the 'AIDS crisis'.

Already, we see the campaign has begun through a proxy war fought around the Safe Schools program. We have also seen *The Australian* newspaper's continued an assault on ACON's Pride in Diversity program, an initiative through which employers promote lesbian, gay, bisexual, transgender and intersex (LGBTI) workplace inclusion. We see in these attacks a diligence in trawling our websites, our networks and our histories for ammunition and points of weakness.

We face a similar prospect of HIV social research being misused by those who mean our communities harm. Pre-exposure prophylaxis (PrEP) is a prime example where this is likely to occur. In 2016, we will move from the inner circle of early adopters to more widespread use. The apparent contract between the gay community and the Australian public – that our sexuality will be tolerated if we put a condom on it – will be breached.

In upcoming Annual Surveillance reports – due in late 2016 for the 2015 year, we should start to see the early effects of PrEP, with concomitantly increasing condomless sex, or as it more commonly known, sex, plus increases in treatable sexually transmissible infections (STIs). Accompanying the tables and figures of data, I'd love to see a narrative about a middle-aged gay man talking about what it means to have sex without anxiety for the first time. There are plenty of those stories around at the moment. But I don't see that happening.

The point here is the same point as I make for the plebiscite. Data without context can hurt. And this is why we need social research. Because it's rich, it's thick and it's sticky. It is concerned with context, with meaning, with interpretation. It provides for the dimensionality of our lives. It is uncertain. It defers. It is curious. It is sense-making.

This year we celebrate 25 years of the Centre for Social Research in Health and its forebear. In the early years of the

Australian HIV response, we were blessed with an abundance of social research undertaken by our research centres and by independent researchers. And it was wide in disciplinary scope: sociologists, linguists, anthropologists, historians, political scientists, social psychologists, visual art and literature scholars, legal scholars, geographers, educators, economists, and probably a few philosophers, each drawing on their rich theoretical traditions and methodologies as they sought to describe and reveal the extraordinary social phenomena of HIV.

Australia continues to have an abundance of world-leading social and other research, but it is narrower now, more limited in disciplinary scope and in its objects of enquiry. Contemporary funding arrangements and limits, together with researcher's interests, no doubt pull against the possibilities of the past. And we shouldn't unduly imagine a rose tinted past or project it nostalgically onto the future, but we should be mindful that as our field of social research narrows, so too do our analyses of the epidemic. That seems to me to be a problem, especially if the remaining disciplinary focal points are partial in the story that they tell.

In reflecting on its 25 years, I would call upon the Centre for Social Research in Health, together with the Australian Research Centre in Sex, Health and Society and our other social research centres and colleagues, to do more to reflect on the narrowing of disciplinary activity and to be active and clever in

tackling it. Governments have an interest in this, but they may struggle to realise it. We must help them. Communities also have a deep interest in a rich disciplinary field, and if our organisations can assist in the task at hand, we are happy to do so.

What then, of the agenda for our newly re-imagined and revitalised social research program? With our freshly minted array of arts, humanities and social science scholars poised before us, pens aloft as they ponder what problem to tackle, what is the agenda that we would set for them? For my part, I'd like to propose five intersecting issues.

First, I'd like you to put to bed the homophobic lie of gay men's complacency in the face of the HIV epidemic.

This is a lie long supported through the abuse of social research findings and it's time it was skewered once and for all. The current moment in HIV for gay men is quite extraordinary. We are surrounded by evidence of continuing adaptation in gay men's social and behavioural responses to HIV, in relations between HIV-negative and HIV-positive men, in advocacy for better policy, technology and service access, and in our struggle to live through and end HIV. The story of those adaptations and mobilisation is not to be found in questions about whether someone would consider using PrEP, or at least not only there, but in the literally thousands of registrations gay men have made to websites for access to trials of this medication, in gay men's efforts to work around our health system and personally import PrEP, and in the online forums, activism and community organising taking place while we wait for governments and Australia's drug regulatory system to catch up with our demands.

Second, I'd like social research to take a renewed interest in our communities' organising and organisations. If we accept that HIV is a social phenomenon, then it must follow that the ways in which we organise and our capacity to organise matters to our collective and individual practices in response to the epidemic.

With fundraised monies, the Australian Federation of AIDS Organisations (AFAO) and AIDS Councils have commissioned work to help us better articulate and demonstrate the value of community control in Australia's response to HIV. That our communities should need to lead such work, and to fund it, is

disturbing. The value of AIDS Councils' knowledge and expertise; the importance of the credibility and community trust of AIDS Councils; and the value of AIDS Councils' understandings of and embeddedness within communities, should be matters of deep interest to social researchers. AFAO and AIDS Councils implicitly know and understand the value that we create. But that matters little when governments defund our organisations – such as in Queensland and South Australia – or require us to compete with public sector agencies and corporations for funds. We can't blame governments for not heeding the evidence of our value if that value hasn't been adequately documented, but I do call on social researchers to look at these questions and to help governments in their task and protect our communities' organising capacity.

Third, let's talk about community. In the same way we speak of a partnership that includes government without differentiating its bureaucratic and political apparatus, we speak of community in ways that homogenise and obscure its diversity. Here, I speak not only of the diversity within communities, but the diversity of communities. The history of gay, sex worker, drug user and HIV-positive peoples' responses to HIV is not uniform or singular, and nor are their contemporary manifestations or probable future trajectories. To deny the distinctiveness and variation of these responses is to mislead us about the possibilities of contemporary HIV prevention, the nature of the tasks we face within our communities and our communities' capacities to achieve our goals.

To pursue and present behavioural and epidemiological data acontextually, without reference to community capacity and goals, or to the social and political contexts that order and constrain those capacities, and only with reference to public health objectives, is to do our communities a disservice.

Fourth, we must do better to understand both the centre and the margins, and we must do so consideredly and without acrimony. Gay men continue to bear the brunt of Australia's HIV epidemic epidemiologically, historically, including in our grief, through shared experience, by public association and through the intrusion of the state into our private lives. We must understand gay men in order to end HIV. And we must understand

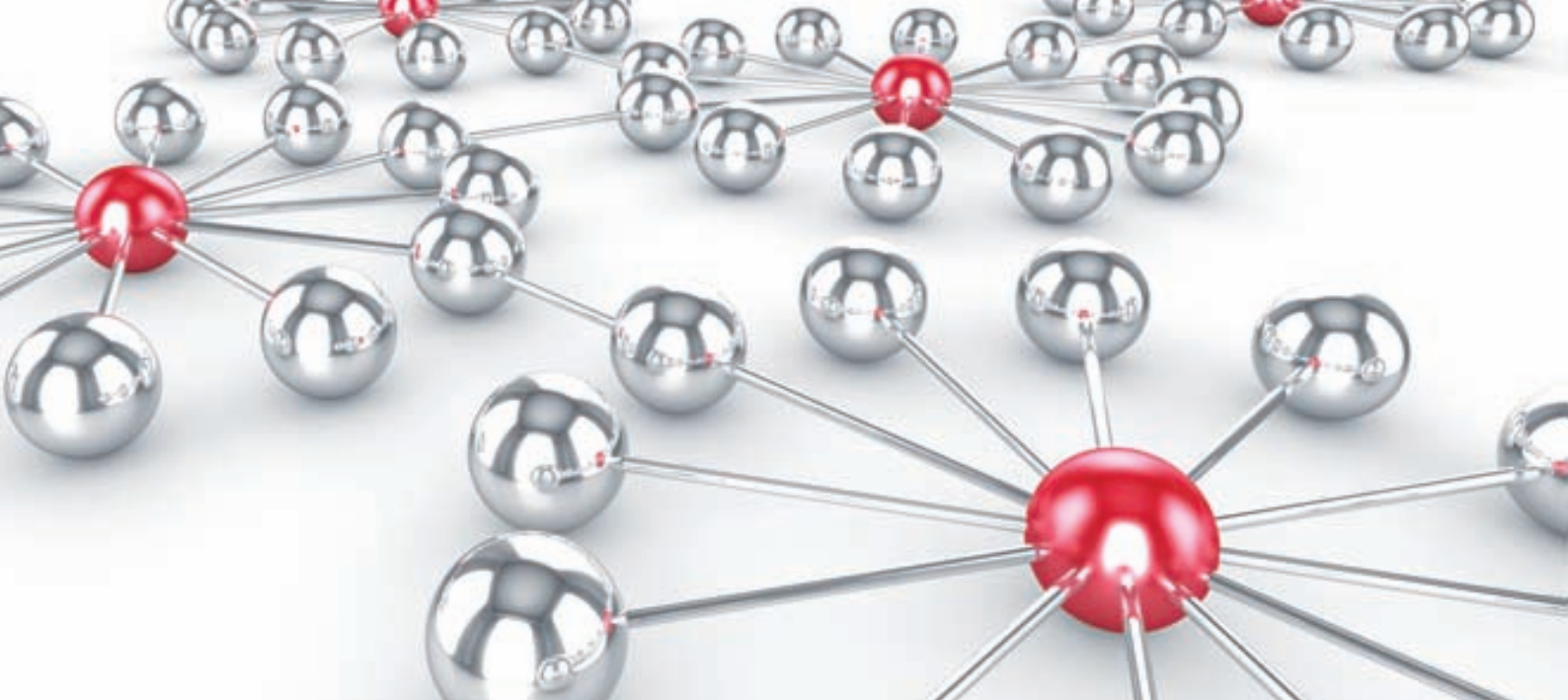
others: including those who also have been historically partnered with the epidemic, those who are disproportionately vulnerable to HIV including Aboriginal and Torres Strait Islander communities, and those whose intersections with the Australian epidemic are more dispersed, but whose experiences we must understand in order to respond. There is in this, the challenge of proportionality for funders and research administrators in an environment of resource scarcity and the discipline for all of us of research planning. We can do much better on this, but we must do so without the divisive and blaming politics that casts the burdens of the HIV epidemic experienced by gay men as somehow a privilege that others should be able to enjoy.

Finally then, to number five: ending HIV. I believe we can end HIV in Australia.

I am extraordinarily proud of the enduring and contemporary efforts of our communities to do so. Our governments are lucky to have us. Ending HIV looks different across our communities. For some, it's the continuing struggle to prevent an epidemic even as governments disinvest in the infrastructure and programs necessary to do so. For others, it's to understand how vulnerable we are to the emergence of HIV and to build the foundations for responses to it. For others still, it is to break the back of the endless cycle of transmission and savagely drive down new infections. In this latter respect, this is the short- to medium-term task and at some point we will succeed. Then the enduring task starts. The proportion of infections will have shifted; in some places, particularly the West, it already has.

Operating across many communities, with varying epidemiologies and community capacities, will stretch all of us. Sustaining gains will take more work, not less. Getting from 90 to 93% will be much harder than getting from 50 to 53%. We must put aside the magical thinking that we will be shutting up shop in 2020 and start our social research planning now for the longer-term trajectories of HIV. At least until we have a cure, social research has a vital role to play.

Darryl O'Donnell is Chief Executive Officer at AFAO.



The Nous Project: exploring the value of the community-based organisations in Australia's HIV response

By the Nous Group

Australia's response to HIV is widely recognised as one of the most successful responses to HIV/AIDS in the world. The Australian response is lauded internationally, and is characterised by tolerance, innovation, agility and partnership.^{1,2,3}

Australia's HIV epidemic has been largely contained to gay men. It is well recognised that gay communities in Australia have been instrumental in the success of Australia's response to HIV; the gay community mobilised early and as a collective to contain the epidemic.

In addition, Australia has been an innovator in harm reduction approaches. It was an early adopter of needle and syringe supply programs, with one state government supporting a medically supervised injecting room in the late 1990s. Since the early days of the epidemic, HIV-positive people have been assured access to affordable treatments as they became available.⁴

All of these gains required political effort from the communities most affected by HIV. The position of community-based HIV organisations (CBOs) in the Australian response immeasurably assisted this effort.

However, the context for CBOs is changing on all fronts:

- **The epidemic is evolving.** The Australian epidemic has had distinct phases and is still evolving. The initial phase was from early emergence of the virus to the introduction of effective antiretroviral therapy (ART). The response then shifted to focus on treatment and managing chronic disease. Currently, we are in the 'treatment as prevention' phase.
- **Community-based HIV organisations are becoming more mature and diversified.** Community organisations erupted from within the affected communities that were under direct existential threat. Over the past 30 years they have developed into more sophisticated health promotion organisations. Many have now expanded to tackle health and social issues other than HIV (in adaptation to working to maintain the low incidence environment).
- **The breadth of non-government organisations (NGOs) working with the affected communities is changing.** Whilst many NGOs operate in the health and social services sectors, few are organically connected to community. Many are ignorant, at best, about the needs of lesbian, gay, bisexual, transgender and intersex (LGBTI) communities,

people who use drugs (PWUD) and sex worker communities. However, a number of NGOs have recognised they have LGBTI clients and are trying to develop better capability and practices to serve these communities.

- **Changing health priorities and the loss of 'corporate memory' are impacting the relationship with government.** Historically community organisations enjoyed bipartisan support. Governments attempted to leverage their knowledge and expertise to fight other communicable diseases (e.g. in attempting to convince AIDS Councils to become AIDS and Hepatitis Councils in 1996). The loss of corporate memory on the effectiveness of community organisations and the tendency for all government funding to be competitively tendered is impacting the funding arrangements and sustainability of AIDS Councils (and other CBOs).

The effects of these changes amplify each other. Community-based HIV organisations are concerned about losing funding and the ability to track and contain the epidemic and other health needs within their communities as the sector and the epidemic evolves.

Summary of Nous Group findings

In early 2016, AFAO and the AIDS Councils decided to commission independent consultants to identify the implications of the changing environment in which community-based HIV organisations are operating. The Nous Group (Nous) was engaged to assess the evidence for the HIV sector's belief that the success of the Australian HIV story – in the past and into the future – relies on a strong community-based response, working at the centre of the Australian HIV partnership.

AFAO and the AIDS Councils were keen to have an objective and documented account of the strength and continuing salience of their core value proposition in this changing environment. The epidemic is undergoing another major change, with the implications of treatment-based prevention coming into focus, and much of the familiarity of the Australian HIV history within public health and funding organisations has fallen away.

In addition, government departments are tendering many more public health functions competitively and non-community embedded NGOs are claiming an ability to work with HIV affected communities, including LGBTI communities.

Nous set a high standard to test the hypothesis that a community-led response is essential to the workings of Australia's HIV partnership, using four key lines of enquiry (KLEs) to structure data collection and analysis activities. These were:

1. What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?
2. What are the features of the community-based HIV response that explains any difference?
3. How has the epidemic and the health needs of communities changed?
4. How can governments be confident that the community-based response will continue to be effective?

Nous' data collection methods included:

- a review of AFAO and AIDS Council documentation
- a literature scan of peer reviewed and grey literature, and
- interviews with AIDS Councils and other key informants (other HIV CBOs, government and researchers).

Nous found strong evidence that community-based organisations were and will continue to be critical to the success of Australia's ongoing HIV response.

To be prepared to endorse the proposition, the Nous team sought strong evidence for each of the four KLEs. That is, there not only needed to be strong evidence that the community-based response had been essential in Australia's success to date but there also needed to be strong evidence to explain exactly why this was so; what features of the response to date had placed the community-based sector so centrally?

Then, in addition, the Nous team sought a clear and evidence based understanding of changes in the epidemic, through its key transformational changes, including the current impact of biomedical treatments as a powerful form of prevention intervention. The Nous team's test here was to understand the changes in the epidemic, in order to understand the basis of the continuing claim for salience from the community-based sector.

Finally, the Nous team explored evidence to support an assurance to government (and the sector's own communities) that the community-based HIV sector will remain agile and relevant to the evolution in the HIV epidemic in Australia and to other health issues confronting its communities.

On all of these measures, against each of these tests, the Nous team was satisfied that the evidence we examined did indeed support each of the propositions needed to support the overall hypothesis, that the HIV CBOs have played and are well placed to continue to play a key role in a world-leading HIV epidemic response.

At the core of this assurance is the ability of these community embedded organisations to: know first the issues and trends within the affected communities; to be able to talk frankly and effectively to members of the affected communities who would not necessarily so engage with mainstream health services; and to access the substantial professional expertise they have also gained to form extraordinary partnerships with mainstream health services.

Table 1 (on page 14) is tabulated a summary of the findings of the Nous team's findings.

In conclusion, the Nous team would reinforce the claim of the HIV CBOs that they have a specific and privileged relationship with HIV-affected communities. For interventions that require mobilisation of those communities, or groups within them, it is pragmatic and evidence based to utilise the capability of these organisations.

Nous would also echo the view put to our team by the HIV community-based organisations that they understand the motive to broaden engagement of other NGOs. Indeed, other NGOs becoming more supportive and effective, for example, with LGBTI, sex worker or PWUD communities is a welcome development for a whole range of service offerings.

However, for public health measures which require community action, especially relating to the most intimate of behaviours that are central to community identity, the evidence is strong that CBOs genuinely have a unique position.

References

- 1 Feacham, R. (1995). *Evaluation of the National HIV/ AIDS Strategy*. Commonwealth Department of Human Services and Health, Canberra.
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- 3 Yang, M., Prestage, G., Maycock, B., Brown, G., de Wit, J., McKechnie, M., et al. (2014). The acceptability of different HIV testing approaches: Cross-sectional study among GSM in Australia. *Sexually Transmitted Infections*, 90(8), 592–595.
- 4 Feacham, R. (1995). op. cit.

The Nous Group is a leading Australian management consulting and leadership development firm, engaged by AFAO and the AIDS Councils to investigate the implications of the changing environment in which community-based HIV organisations are operating. The full Nous report will soon be made available on the AFAO website.

Table 1 Summary of findings

KLE 1: What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?	
Finding	Description
Community-based HIV organisations are part of a strong partnership network between government, health practitioners, researchers and HIV affected communities.	<ul style="list-style-type: none"> ■ There is no standard definition for 'community control' in existing literature. ■ However, key elements define community-based responses, elements which have enabled these organisations to play a pivotal role in the overall response to HIV in Australia. Community-based responses are: <ul style="list-style-type: none"> – initiated, designed and implemented by the community – responsive to the evolving needs of the community – often enacted through partnership with mainstream – dependent on community for authority.
There is strong evidence that compares the results achieved by community-based HIV organisations to non-community organisations.	<ul style="list-style-type: none"> ■ Community-based responses have been more effective than traditional public health approaches. Case studies can be used to demonstrate their comparative effectiveness, such as: <ul style="list-style-type: none"> – Australia's success in responding to HIV versus other countries that did not use a community-led response (and were less successful) – The increased infection rates in Queensland and Victoria when the HIV partnership between government and supporting communities broke down.
There is evidence that community-based HIV/AIDS organisations were key contributors to the overall response.	<ul style="list-style-type: none"> ■ Australia responded to HIV through a partnership model, which is widely credited as the reason for our success in responding to the epidemic. ■ Community-based HIV/AIDS organisations play a distinct role in the overall partnership response.
KLE 2: What are the features of the community-based HIV response that explains this difference?	
HIV CBOs have unique features that enable them to provide trusted, relevant and efficient services and programs.	<ul style="list-style-type: none"> ■ HIV CBOs are embedded within their affected communities, which supports a deep understanding of the contemporary issues and effective solutions. ■ A number of examples demonstrated how HIV CBOs were aware of behavioural and other changes in the HIV epidemic and able effectively to address these changes arising ahead of other health organisations. ■ HIV CBOs have attained unusually high levels of professional knowledge in specific domains, which informs successful service delivery. ■ HIV CBOs typically have high credibility with mainstream service providers based on their authority within the affected communities.
The combined value of HIV CBOs unique features place them in an advantageous position to respond to the HIV epidemic and other emerging health threats.	<ul style="list-style-type: none"> ■ HIV CBOs have permissions that many other public service organisations do not have. ■ HIV CBOs work in partnership and collaboration with a broad range of organisations. ■ AIDS Councils and other HIV CBOs are recognised as leaders within their respective fields of expertise.
Programs and services delivered by HIV CBOs are cost effective.	<ul style="list-style-type: none"> ■ Overall, existing evidence shows AIDS Council services and programs are cost effective when compared to approaches by organisations that are not community-based. This is due to: the cost-benefits of volunteers; greater reach; self-generated funds; and efficient data and information collection.
KLE 3: How has the epidemic and the health needs of communities changed?	
Australia's HIV epidemic has been characterised by a strong community response and can be historically grouped into three phases.	<ul style="list-style-type: none"> ■ There have been three phases in Australia's epidemic. Each is marked by significant changes in prevention and treatment options. In each phase, the HIV CBOs have led efforts to respond to the changing needs and requirements of communities affected by HIV.
New communities of people affected by HIV are emerging.	<ul style="list-style-type: none"> ■ New diagnoses have been rising among some Aboriginal and Torres Strait Islander communities. ■ New diagnoses have been rising among people who travel to and come from countries of high HIV prevalence.
New health threats are emerging in HIV affected communities.	<ul style="list-style-type: none"> ■ HIV interacts with numerous other health issues and affected communities increasingly focus on a range of these other health concerns. These include: STIs, hepatitis and sexual health; mental health and alcohol and substance use; and comorbidities and aged care.
Non-health issues also have a large impact on the lives of communities affected by HIV.	<ul style="list-style-type: none"> ■ These include: legal and policy issues; the re-emergence of politician led homophobia; and stigma and discrimination.
KLE 4: How can governments be confident that the community-based response will continue to be effective?	
There is strong evidence that AIDS Councils have changed their strategies and will continue to adapt to meet changing needs.	<ul style="list-style-type: none"> ■ HIV CBOs have a strong track record of adaptability. As Australia's epidemic has changed, HIV CBOs have effectively adapted their responses and they are continuing to do so.
The inherent features of HIV CBOs will enable them to be adaptable.	<ul style="list-style-type: none"> ■ These inherent features are community embeddedness, professionalism of staff, extensive networks, democratic structures and the capacity to mobilise.



Evaluation of AFAO's Health Promotion Program, 2012–2014

By Rigmor Berg

Background

For the last 30 years, the development and national implementation of HIV and sexually transmissible infection (STI) prevention and health promotion programs has been a key area of work for the Australian Federation of AIDS Organisations (AFAO). This work has been carried out by the AFAO Health Promotion Program (AHPP), in consultation and cooperation with the AFAO membership.

This year, following a competitive tender process, AFAO's health promotion program is coming to a close.

As a matter of sound health promotion practice and commitment to continuously reflect upon and improve the quality of our health promotion work, AFAO has routinely sub-contracted an external consultant to carry out an independent evaluation of a selection of key program components on an annual (or biennial) basis.

What follows is a summary of an evaluation conducted by Dr Rigmor Berg of the current AFAO health promotion program (2012–2014), accompanied by a brief retrospective of key AFAO health promotion campaign images (pages 18–25).

AFAO acknowledges the hard work and input of all past and current AFAO health promotion staff, past health promotion managers – the late Alan Brotherton, Dermot Ryan, and in particular, Simon Donohoe, who leaves AFAO in June 2016 after almost 13 years of service leading the AFAO Health Promotion Program team.

Introduction

This article summarises an evaluation of the AHPP conducted in 2014. The evaluation found that the AHPP 2012–14 was extremely valuable and successful in its aims of identifying priorities, developing policy, building capacity within member organisations and providing campaign materials and information resources suitable for diverse populations and locations.

All program initiatives were assessed to be relevant to demonstrated needs and consistent with the objectives and priorities of the *Seventh National HIV Strategy 2014–2017*. They were effective in engaging their target audiences, providing useful information, influencing behavioural intentions and, where measurable, actual behaviours.

The evaluation found that the program was well structured to meet a wide range of HIV health promotion needs, with processes that ensured:

- constant monitoring and analysis of social, epidemiological and medical research findings to identify issues as they emerged, determine priorities for action and develop effective strategic responses
- effective, high quality health promotion campaign materials and information resources were available for gay and other men who have sex with men (MSM) in all states and territories of Australia, with consistent messaging throughout,

taking account of the diversity of these populations and the social milieux in which they live, regardless of the varied and fluctuating support given to this purpose by state/territory governments

- valuable health promotion resources for HIV-positive people, and
- valuable health promotion resources for Aboriginal and Torres Strait Islander people.

Meeting the needs of the AFAO membership

To appreciate the value of this program, it is important to recognise that AFAO's state/territory-based members are highly diverse in size, stability and level of funding, the scope of their responsibilities, the populations they serve and the community and services infrastructure they have to work with. Their needs vary a great deal and a simple model cannot serve all equally well.

AFAO's member organisations considered the AHPP to be extremely valuable. For some, it had been indispensable in their circumstances throughout the evaluation period. The smaller AFAO members would have provided a much lower standard of health promotion services without the benefits of the AFAO program's intellectual leadership and capacity development, as well as AHPP developed or facilitated campaign materials and information resources. While the largest AIDS Councils can function well without AHPP support,

they have also benefited from the sharing of information, analysis, ideas and initiatives made possible by AHPP.

AHPP research, review and consultation processes for identifying priorities and developing insightful, evidence-based and practice-oriented discussion papers, effective campaign concepts and broadly or specifically appropriate information resources were sound. However, implementation of campaigns and distribution/promotion of information resources by member organisations at the time of data collection for this evaluation were uneven. The unusually brief time frame for this evaluation (due to the health promotion function being put out to tender) meant that some initiatives had not yet been implemented in all states and territories. Other contributing factors included limited human resources and high staff turnover in the smallest organisations, dramatically changed circumstances (two members lost their state funding) and competing priorities.

Timing made the main evaluation methods relied upon in preceding years (online surveys and expenditure to website click ratios) unusable, so the main sources used were reports from member organisations and other relevant service providers, website traffic analysis and direct feedback from target group members through focus groups and interviews conducted in all Australian states and territories, together with some pre-existing evaluation reports and other documentation.

Campaigns: key findings

During the period examined by the evaluation, the AHPP developed two action-oriented websites with associated promotional materials (Time to Test and Your Body Blueprint) and three print resources (Taking a Look, Our Team and Us Mob and HIV booklets) for national distribution. (Images from each of these campaigns appear on pages 18–25.)

Time to Test

The evaluation found that the Time to Test campaign was soundly based upon and guided by epidemiological, psychosocial and formative social marketing research findings. Focus group responses showed that the materials were effective in engaging a wide range of gay men. The video was generally considered entertaining, clear and persuasive. The poster and web page designs effectively addressed several distinct target groups and research participants responded in keeping with campaign intentions, each attracted by images and messages tailored to suit their own community segment.

Campaign messages addressed the need for testing and some common psychological and practical barriers to testing, encouraging sexually active gay/MSM to test more frequently or for the first time and to set up regular reminders. All research participants found the information and arguments presented persuasive and, although implementation of this campaign had barely commenced at the time of evaluation, many had already responded by getting HIV tested and/or registering via the site for regular reminders to get tested. Website analytics clearly showed that advertising on smart phone apps and online social networking sites was a very effective way to drive traffic to the website.

Your Body Blueprint

Evaluation of the Your Body Blueprint website (AHPP's main initiative for HIV-positive people), found that the resource was extremely effective. However, at the time of evaluation, promotion of the website by AFAO and National Association for People With HIV Australia (NAPWHA) member organisations was very uneven, probably in part due to dissolution of the AFAO-NAPWHA health promotion partnership, though some participating organisations

had done this well. The effectiveness of the recommended promotional strategy was evident in the traffic to the website from the two states where allocated funds had already been appropriately spent.

Focus group feedback from diverse HIV-positive people showed that Your Body Blueprint is an extremely useful health information and referral resource. It provides much that is valuable for people living with HIV, whether they were recently diagnosed or have been HIV-positive for a long time; whether they are male, female or transgender. People who had been diagnosed recently indicated particular interest in accessing the material on this website, which is far more extensive than the information treating doctors can deliver or patients can absorb within brief appointments.

Feedback from HIV-positive people also identified scope for making valuable components more accessible and extending the content to better meet the specific needs of groups including HIV-positive women, trans people, heterosexual men, dependent and people who use injecting drugs, Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CALD) backgrounds.

Taking a Look

While the trend in HIV health promotion is towards using a simple message campaign to alert target populations to the availability of more detailed information online, there remains need for a hard copy print resource that succinctly addresses all core areas of knowledge men need to participate safely in gay communities, and Taking a Look does this admirably. Although the resource was seen to primarily serve young gay men and others new to gay community life, all focus group participants said they had learned something new, and many said they had learned a lot. All participants strongly praised the clear and accessible language, and some asked permission to keep the samples for later reference or to show friends.

Our Team

Our Team is an attractive print resource that effectively addresses the need for clear communication within gay relationships and provides a framework for explicitly negotiating sexual health safety agreements. It was very well liked by focus group participants. Many thought it would be most useful as a workshop

... the AHPP 2012–14 was extremely valuable and successful in its aims of identifying priorities, developing policy, building capacity within member organisations and providing campaign materials and information resources suitable for diverse populations and locations ... AFAO's member organisations considered the AHPP to be extremely valuable. For some, it had been indispensable in their circumstances throughout this period.

discussion tool or targeted handout for young gay men, helping them to think through the issues and start negotiated safety conversations early in relationships. Some thought it would also help gay men in long-established relationships to revisit earlier agreements to see whether they need updating.

National campaigns

The AHPP also commissioned campaigns for national rollout, specifically *The Drama Downunder* developed by VAC (Victorian AIDS Council) and *Ending HIV*, developed by ACON. This approach was valuable for several reasons. It provided very high quality, well researched, professionally developed and tested materials to smaller AFAO members who reported that they lacked the staffing and resources to produce something comparable themselves. The AFAO national rollout of these campaigns ensured that messages were consistent across the whole of Australia, which is important because gay identifying and other men who have sex with men are highly mobile populations. This also reduced duplication of work, ensuring that available funding could be used in the most cost-effective way.

Evaluations conducted over three phases of *The Drama Downunder* showed this to be a very effective campaign. It achieved very high recognition and recall rates, particularly in Victoria, where expenditure on advertising and particularly outdoor advertising was highest.

Both online survey and focus group findings suggested that responses to this campaign were very positive, with gay men recognising the value of regular sexual health testing. There was substantial increase in the number of gay/MSM presenting for sexual health testing to the Melbourne Sexual Health Centre, coinciding with *The Drama Downunder* campaign that in Melbourne included promotion of the newly introduced clinic days specifically for gay/MSM. This showed the value of linking campaigns to improvements in related services, as well as the effectiveness of the campaign in promoting behaviour change.

Focus group discussions showed that a wide range of gay men across Australia also responded very positively to *Ending HIV* advertising materials and website,

embracing the concept of community uniting for a common purpose. There was clear understanding of and general agreement with the core messages, and some focus group participants had already presented for testing and/or made use of the testing reminder function in response to this campaign. Recognition was high in locations where the campaign had already been implemented at the time of data collection.

Ending HIV had some overlap with Time to Test in aims, information content and practical tools provided. These campaigns are likely to be complementary in their effect because they deliver consistent messages, but with some differences in appeal for specific audiences.

Campaigns for Aboriginal and Torres Strait Islander communities

AFAO's state/territory members vary greatly in their approach to creating campaigns for Aboriginal and Torres Strait Islander communities, reflecting the diversity of the populations they work with, epidemiology within their state/territory and the terms of their funding. Some AIDS Councils focus on Aboriginal gay men, sistergirls and people who use injecting drugs, specifically, while others take a whole of community approach.

Aboriginal and Torres Strait Islander people are highly diverse in their circumstances, cultural background, language skills, consequent information resource needs and available points of access, so a single campaign or information resource cannot address the needs of all. It is appropriate and useful that AFAO produced or facilitated a range of initiatives, including:

- A detailed information print resource suitable to support Aboriginal health workers working with remote communities as well as for Aboriginal and Torres Strait Islander people with good English reading skills and interest in HIV prevention, testing, treatment or support (*Us Mob and HIV*).
- A campaign design specifically targeting Aboriginal and Torres Strait Islander gay men and sistergirls with clear, simple HIV/STIs prevention and testing messages (*Our Destiny Haz Arrived* developed by Anwernekenhe HIV Alliance [ANA]).

- National access to a suite of entertaining and culturally appropriate HIV/sexually transmissible infections (STI)/Blood borne virus (BBV) education resources targeting Aboriginal and Torres Strait Islander communities generally (*Condoman* website, developed by the Two Spirits Project based at Queensland AIDS Council).
- These initiatives complement the AFAO Health Promotion Program website for Aboriginal and Torres Strait Islander people, *Better to Know*, which provides information about a wider range of STIs and BBVs, a testing reminder service, and an anonymous partner notification service.

In summary, the AHPP for the 2012–14 period was extremely strong and each of the campaigns was successful in meeting its objectives. Some recommendations were made concerning processes and future priorities, including need to better address the specific needs of trans people and need to include Aboriginal and Torres Strait Islander people in general campaigns.

Overall, 2012–14 was an extremely successful period for the program, providing a strong conclusion to AFAO's proud history of 30 years of health promotion work.

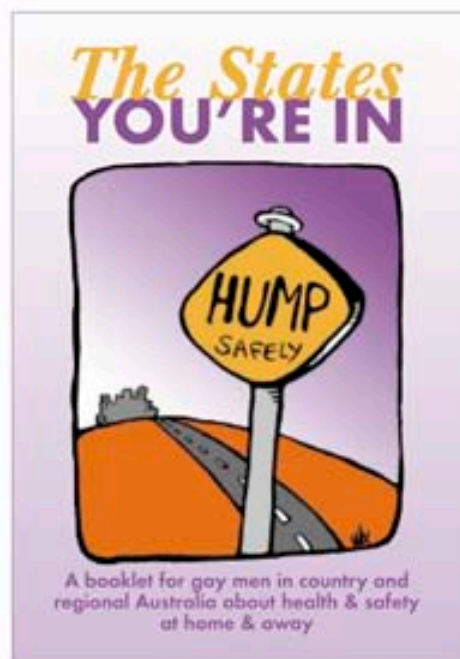
Dr Rigmor Berg BSc(Hons)PhD, Principal of BB Professional Services, has 30 years' experience providing evaluation research services to HIV health promotion clients including National Advisory Committee on AIDS (NACAIDS), AFAO, ACON, Queensland Association for Healthy Communities (QAHC)/Queensland AIDS Council (QuAC), NSW Users and Aids Association (NUAA), Sex Workers Outreach Project (SWOP), Gender Centre, Communicable Diseases Branch of Queensland Health, AIDS Bureau, Drug and Alcohol Directorate and HIV and Related Programs Unit of NSW Health. Contact: rigmor.berg@optusnet.com.au

AFAO health promotion retrospective

2016 marks the end of AFAO's 30-year health promotion program. On the following pages is a retrospective look at some of AFAO's key health promotion campaigns. More images appear in *HIV Australia* online, available at www.afao.org.au



You Are Not Alone (2000) – Booklet in English and Vietnamese. Information for people newly diagnosed with HIV, first published in 2000 and revised with organisation updates in 2015.



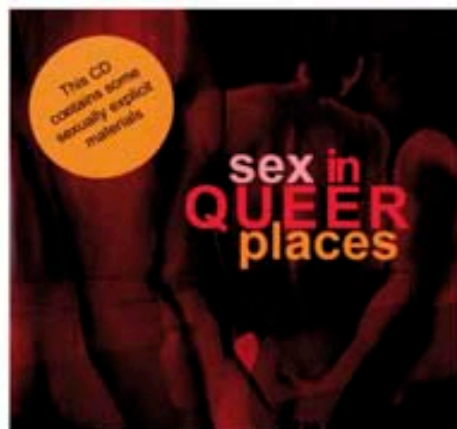
The states you're in (2001) – Booklet. Information for HIV-positive and HIV-negative gay men who live in rural and regional areas, with a focus on travel, sex away from home, and the gay scene in Australian cities.



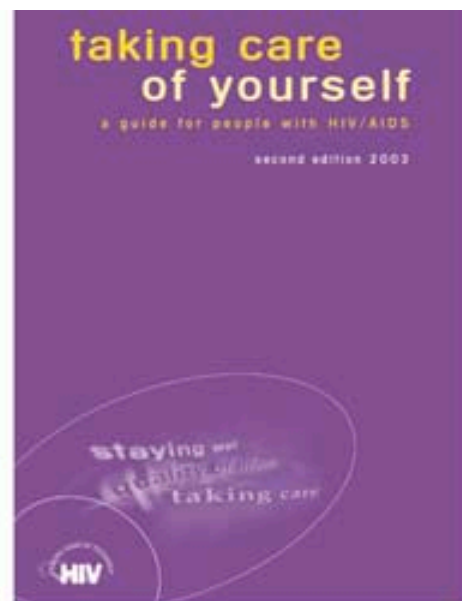
At Home Away – Treat Yourself! (2001) – Poster. This poster encourages people with HIV to plan ahead when travelling and to stick to a regular medication schedule while away.



At Home Away – Seeing The World? (2001) – Poster. This poster asks gay men to think about HIV and sexually transmissible infection (STI) risk when travelling and to pack condoms and lube when planning for a trip.



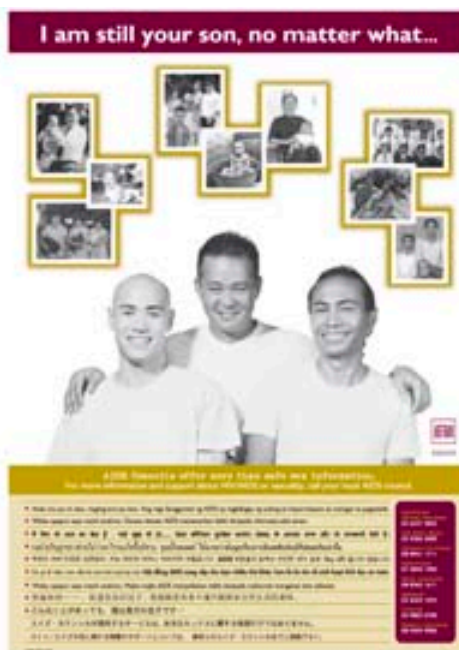
Sex In Queer Places (2002) – Website and interactive CD-ROM. An interactive video game-style resource for gay men exploring a range of scenarios involving sexual encounters and/or drug use. Some of the animations were deemed sexually explicit, and the website was converted to an interactive CD-ROM with a warning about the sexually explicit content.



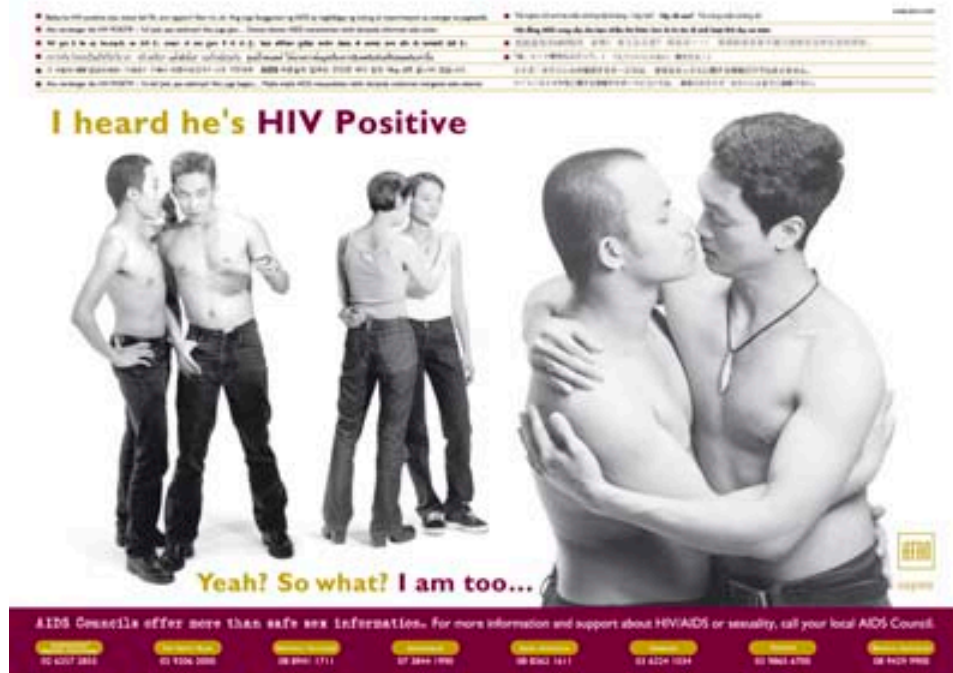
Taking Care of Yourself (2003) – Booklet *Taking Care of Yourself* covers a range of issues relevant to HIV-positive people including support, treatment, hospitalisation, and participation in medical and social research. This revised, second edition was published in 2003.



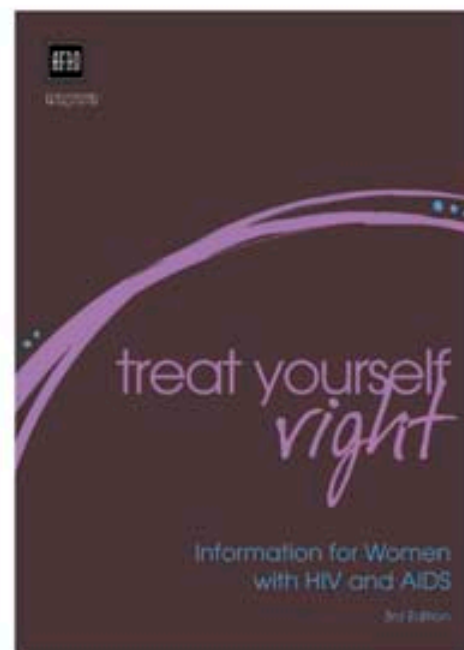
Sistergirls Say – Keep Yourself Covered (2004) – Posters. A national peer-based poster and postcard campaign developed to promote positive self-esteem and sexual health messages. The campaign also aimed to increase awareness about sistergirl and transgender identities among service providers and the broader Aboriginal and Torres Strait Islander community.



Between The Sheets (2005) – Magazine. Information for gay men taking a light-hearted and sometimes tongue-in-cheek look at HIV issues within relationships.



Positive Gay Asian (2005) – Posters. A campaign consisting of three posters targeted at gay Asian men living with HIV and broader Asian communities. The campaign encourage HIV-positive gay Asian men to make contact with their local AIDS Council.



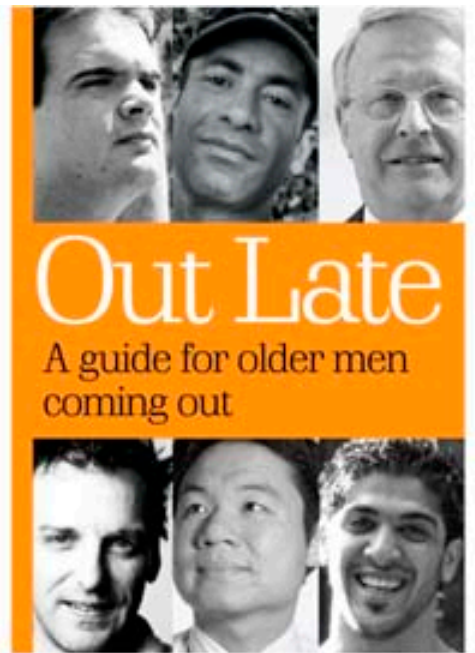
Treat Yourself Right (2007, third edition) – Booklet. Information for HIV-positive women on a wide range of topics, with a focus on health maintenance and HIV treatments information.

AFAO acknowledges the hard work and input of all past and current AFAO health promotion staff, past health promotion managers – the late Alan Brotherton, Dermot Ryan, and in particular, Simon Donohoe, who leaves AFAO in June 2016 after almost 13 years of service leading the AFAO Health Promotion Program team.

AFAO health promotion retrospective



We're Family Too! (2005) – Poster. This campaign aims to reduce discrimination, vilification and stigmatisation experienced by Aboriginal and Torres Strait Islander gay men, lesbians and sistersgirls, particularly in the area of community-based service provision.

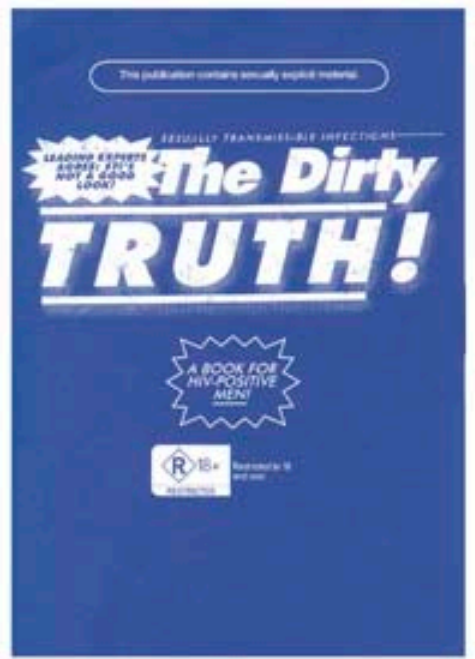


Out Late: A guide for older men coming out (2007–2009, 2nd edition) – Booklet.

Information about sexual identity and coming out as an older gay man as well as important information about health and safe sex.



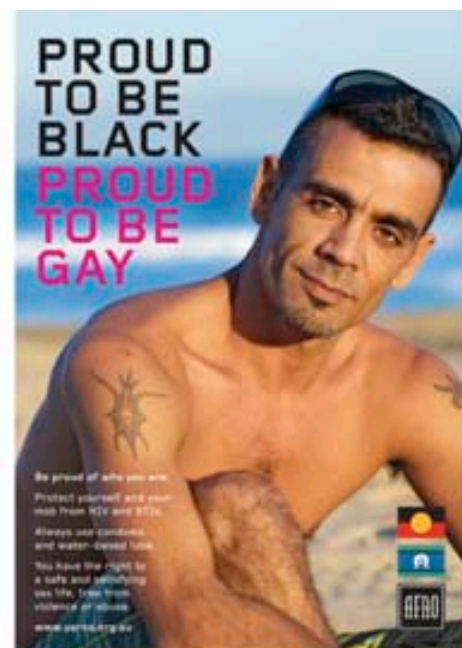
The Drama Downunder (2007–2016) – Website, booklet, posters and large format outdoor advertising. A national campaign produced for gay men about STIs and the importance of regular sexual health checks.



The Dirty Truth (2008) – Booklet. *The Dirty Truth* provides information on STIs for HIV-positive gay men, using explicit homoerotic imagery laid out in a camp tabloid style. The booklet has a R18+ rating and comes in a sealed wrapper with blue and white cover sheets stating the rating.



Managing Side Effects (2008) – Booklet. Information about managing side-effects through complementary therapy, medical and drug treatments. The booklet also includes an extensive glossary of terms and information about how to find a qualified practitioner in various complementary medicine modalities.



Proud to be Black, Proud to be Gay (2009) – Posters. A series of three posters that encourage condom reinforcement and peer-based education among Aboriginal and Torres Strait Islander gay men about HIV/AIDS and STIs.



Real time: the truth about fucking without condoms (2009) – Booklet. A workbook-style booklet designed to assist HIV-positive and HIV-negative gay and bisexual men to stay safe, and reduce the risk, stress and worry associated with sex.



Ahead of Time: A practical guide for growing older with HIV (2010) – Booklet. Information about HIV and the ageing process, relevant to the lives and health of people living with and growing older with HIV.

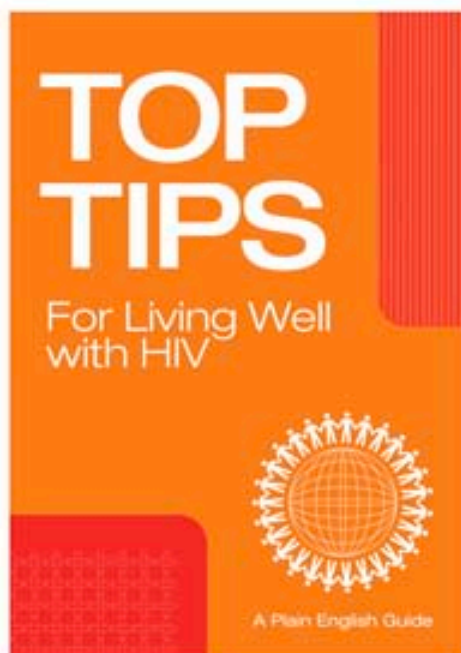
AFAO health promotion retrospective



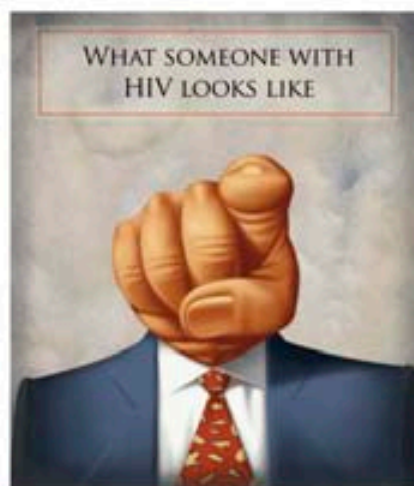
HIV-positive gay sex (2011, third edition) – Booklet and website. Information about HIV, sex and intimacy, written from an HIV-positive gay man's perspective.



Straight Talking (2011) – Website. A best practice guide about HIV and sexual health promotion for workers in Aboriginal and Torres Strait Islander sexual health.



Top Tips For Living Well With HIV (2007–2011) – Booklets and website. Information for HIV-positive people about the day-to-day management and treatment of HIV, and links to further information and support. First published in 2007, the resource was expanded and redeveloped into a website and plain English booklet in 2009. In 2011, the plain English version was translated into four languages (Amharic, Vietnamese, Thai and Arabic).



Fear Less Live More (2011) – Posters and website. The Fear Less Live More campaign encourages gay men to communicate more openly about HIV in sexual settings.



Let's talk about it! (2012) – Website. An interactive website designed to assist gay men to build healthier relationships by encouraging them to talk with their boyfriends or partners about relationship agreements.



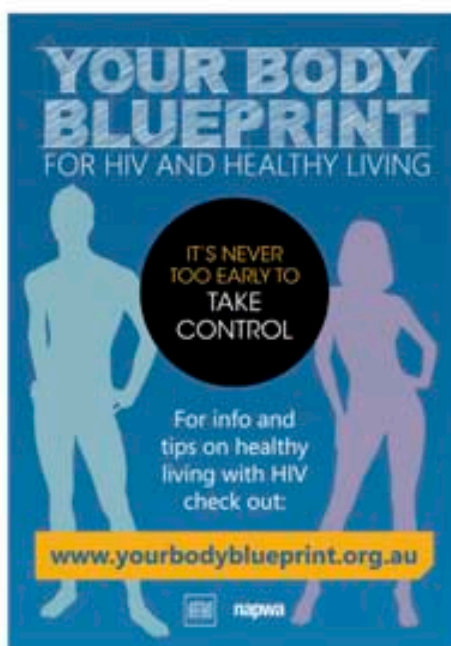
Better to know (2012) – Website, poster and cards. The Better to Know campaign provides young Aboriginal and Torres Strait Islander men and women with information on HIV and STIs. The campaign includes specific information relating to 'men's business' and 'women's business', a partner notification service, a testing reminder service and information about clinics and services split by state and territory.



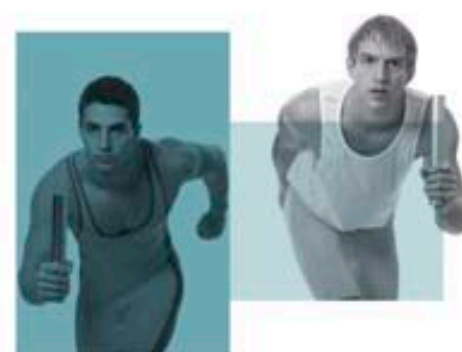
Our Destiny Haz Arrived (2013) – Poster. A national Aboriginal and Torres Strait Islander HIV prevention, testing and treatment campaign.



The New Deal (2013) – Website. The New Deal provides gay men with information about the sexual transmission of hepatitis C and how to prevent it, as well as information on hepatitis C testing and treatment, and HIV and hepatitis C co-infection.

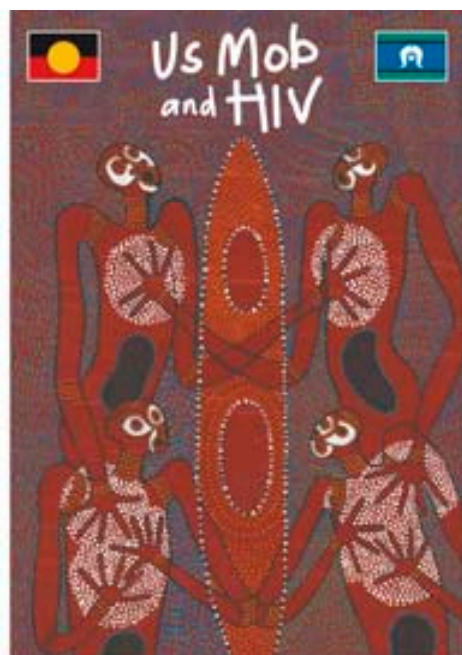


Your Body Blueprint (2013) – Website, posters and post-it notes. A national campaign designed to encourage and support people with HIV to lead healthier lives, reduce the risk of illness, and enhance quality of life.



Our Team (2014) – Website and booklet. This resource aims to support gay men in negotiating sexual agreements within their relationships, using team sports imagery as a metaphor for the approach that couples need to take in keeping each other safe.

AFAO health promotion retrospective



Us Mob and HIV (2003–2014) – Booklet. The third edition of a resource originally published as *HIV/AIDS and Us Mob*, this booklet aims to increase Aboriginal and Torres Strait Islander people's knowledge about HIV and its impacts. It contains basic information on HIV, focusing on transmission, prevention, HIV testing, HIV treatments, health monitoring, care and support available for people with HIV, as well as service contact details.



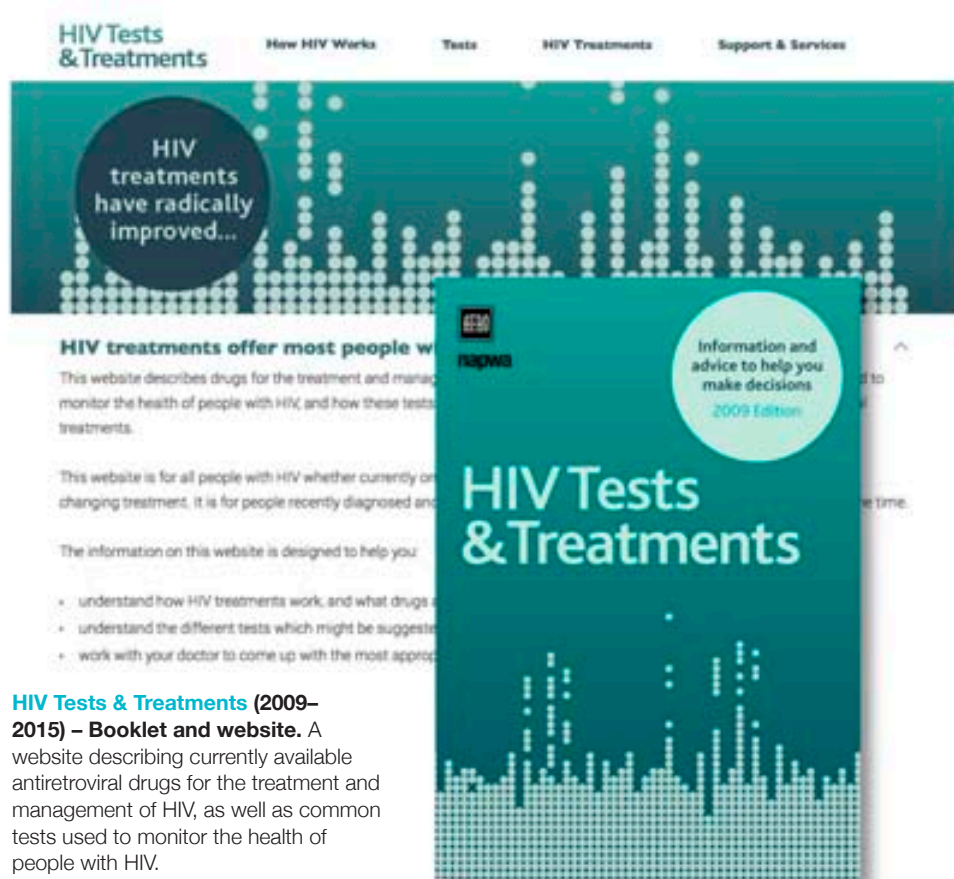
The Bottom Line (2014) – Website, booklets and posters. A campaign for gay men, which promotes awareness of human papillomavirus (HPV) and anal cancer.



Taking a Look (2008–2015) – Booklet and website. Information on HIV prevention for gay and bisexual men. First published in 2008, the booklet was revised and relaunched in 2015 with an accompanying website (www.takingalook.org.au), featuring expanded information on a range of options for HIV testing, prevention and treatment.



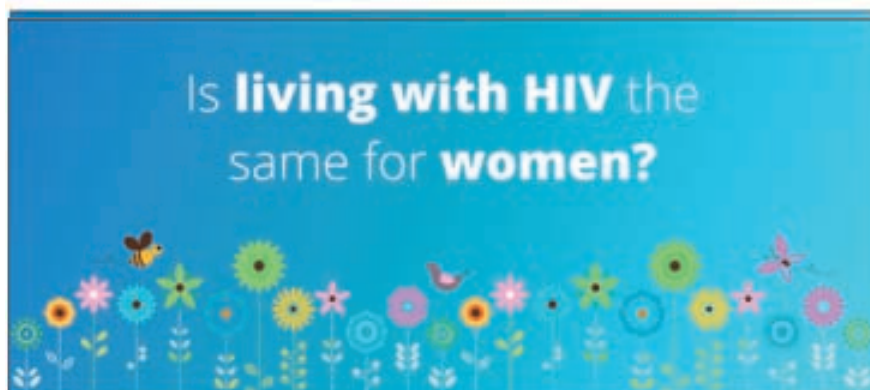
Time to Test (2014–2015) – Website and posters. This campaign encourages gay men to get tested for HIV more frequently. A website and series of posters focus on addressing the emotional barriers to testing, such as fear, shame and uncertainty about the benefits. This poster is from the second phase of the campaign, produced in April 2015.



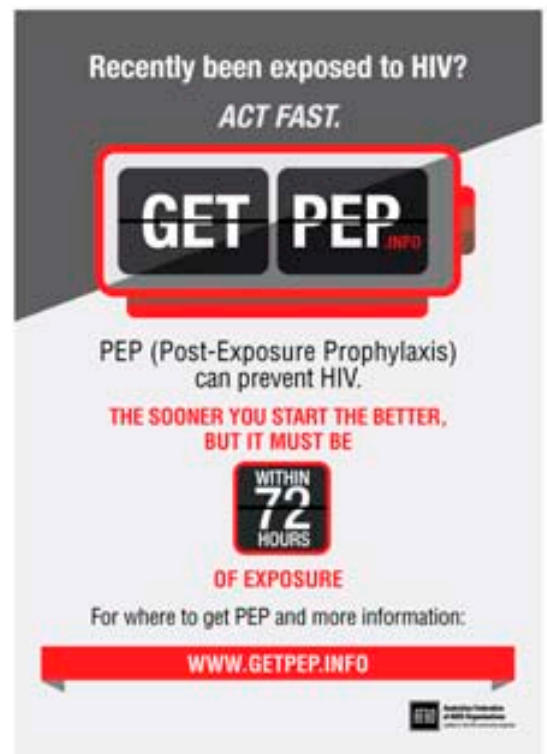
HIV Tests & Treatments (2009–2015) – Booklet and website. A website describing currently available antiretroviral drugs for the treatment and management of HIV, as well as common tests used to monitor the health of people with HIV.



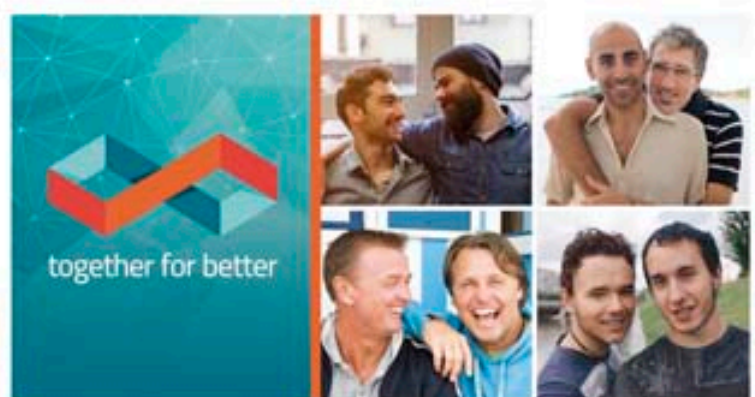
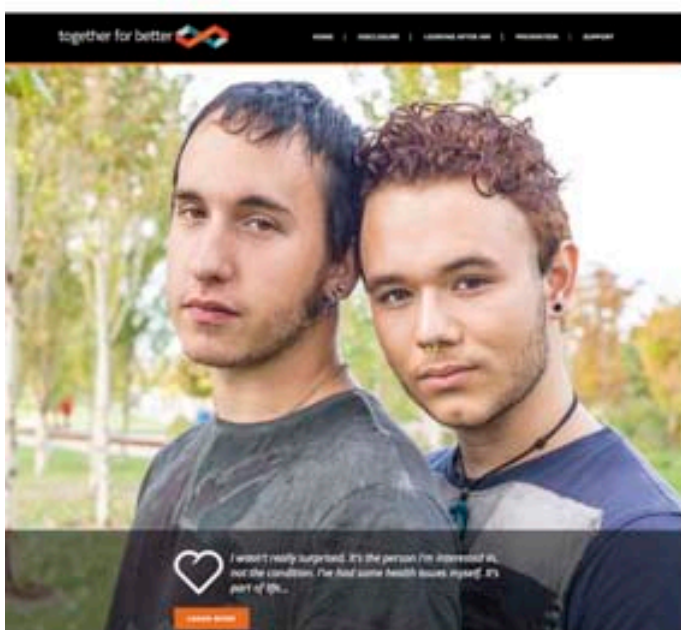
Next Steps (2008–2015) – Website and booklet. A resource for people recently diagnosed with HIV that covers a range of topics and includes real-life stories. The booklet was originally published as *A Positive Diagnosis* in 2003, and was redeveloped and republished as *Next Steps* in 2008. The most recent version of the booklet was produced in October 2015 and a website (<http://hivnextsteps.org.au>) was launched in December 2015.



Women Living Well with HIV (2015) – Website and booklet. A comprehensive resource for women living with HIV, covering topics including disclosure, sex, treatments, having children, keeping well and getting support. The resource was adapted from AFAO's highly-regarded booklet, *Treat Yourself Right* (see page 19).



Get PEP (2016) – Website, poster and cards. A national campaign aiming to increase gay men's knowledge and awareness of PEP (Post-Exposure Prophylaxis).



Together for Better (2016) – Website. Together for Better (<http://togetherforbetter.org.au>) is an online resource for gay men about serodiscordant relationships.



The power of peers: W3 framework for evaluating the quality and influence of peer-led programs

By **Graham Brown and Daniel Reeders**

Introduction

Australia's response to HIV has often celebrated the partnership of affected community, clinicians, research and government. The key role of affected communities has been underpinned by peer-based health promotion and leadership among gay men, people who use drugs, sex workers, and people living with HIV.¹ These programs have needed to navigate and adapt to constantly changing political and stigmatising contexts around sex, sexuality and drug use. The emergence of PrEP (pre-exposure prophylaxis) and TasP (treatment as prevention) has only accelerated the climate of rapid change.

At its core, peer-based health promotion is all about interactions between the program and the communities it works with. However, most traditional evaluations look at programs in isolation, overlooking the impact of interactions with other programs and the community and the broader socio-political context in which the programs operate. This often results in policy commitments to community mobilisation and peer based responses to improve the health of our communities – but with programs contracted, evaluated and managed as information dissemination or generic service provision.

The What Works and Why (W3) Project wanted to really shift the capacity of peer programs to demonstrate the role and influence they play as part of a larger system of public health programs and complex communities and politics. We needed a better way to describe our understanding from both research and practice of what the program is or should be achieving – a better program theory to guide our evaluation.

This article focuses on the development of the W3 Framework, and using PrEP and TasP as an example, illustrates how the W3 framework can be used in practice.

What the W3 Project did

Working in collaboration with ten peer-led programs (Table 1), we used systems thinking and participatory methods to develop a better understanding of how peer-based programs work, formulating a framework to evaluate the role and contribution of peer-based programs and developing methods to best capture and share insights from practice.

What systems thinking brought to the table was an understanding that for peer-led programs, the way communities respond, enhance, adapt, resist or ignore interventions are part of the program, and that this something that should be leveraged.² The systems thinking

Table 1 The W3 Collaboration

Australian Research Centre in Sex, Health and Society, La Trobe University
Australian Federation of AIDS Organisations
Australian Injecting and Illicit Drug Users League (AIVL)
Harm Reduction Victoria
Living Positive Victoria
National Association of People Living with HIV/AIDS
Positive Life NSW
Queensland Positive People
Scarlet Alliance – Australian Sex Workers Association
Victorian AIDS Council
Western Australian Substance Users Association
Funded by the Commonwealth Department of Health

approach conceptualises peer-based programs and the communities and policy environments they engage with as complex adapting systems.

The advent of PrEP and TasP have totally disrupted meanings of safe sex and the way HIV stigma is resisted or reinforced, resulting in community initiated access schemes to facilitate the importation of PrEP outside of the normal health structures. This has resulted in the community, peer-led HIV

prevention programs, and the health system each having to adapt and change in tandem with an environment in flux. Systems thinking helps us to look at the relationship between all the parts of this picture, and assumes the ground will keep moving. Our approach looks for the best leverage points and synergies as the system and the programs continue to adapt and evolve.^{3,4,5,6}

Our work with the ten programs involved a series of workshops with each organisation to draw, articulate and revise complex system maps – like a map of an ecological system – describing what happens during these programs and their relationships with all the components of the community and policy system they are situated within. The aim was to examine how peer-led programs operate, drawing on a range of differing perspectives, including outreach workers, community development practitioners, workshop facilitators, policy and leadership, management and board members. Each of these stakeholders holds a particular perspective, but the pieces of this picture are rarely brought together.

This detailed mapping process required a huge amount of trust from our partners, and was breaking new ground. There is more detail about the approach and methods on our website (www.w3project.org.au). But the key point is that we analysed these complex system maps to draw out the system level key functions, which could be used to better demonstrate the value of investing in peer-led programs.

The W3 Framework

We found that peer-led programs are operating within and between two interrelated and constantly changing sub-systems – the community system and the policy (or sector) system. We found there are four functions that are required for peer-led programs to be effective and sustainable in such a constantly changing environment:

- **Engagement:** How the program maintains up to date mental models of the diversity and dynamism of needs, experiences and identities in its target communities
- **Alignment:** How the program picks up signals about what's happening in its policy/sector environment and uses them to better understand how it works

- **Adaptation:** How the program changes its approach based on mental models that are refined according to new insights from engagement and alignment

- **Influence:** how the program uses existing social and political processes to influence and achieve improved outcomes in both the community and the policy/sector.

To unpack these concepts in more detail, let's again look to the specific example of the community and policy response to PrEP as a way of illustrating how each of these functions works in practice.

Engagement

Identifying the different ways in which PrEP is being used by gay men, and how it may be interacting with meanings of safe sex and stigma, is not limited to listening to clients and doing consultation. It is about the unique relationship a peer-based approach has within its community, achieved by utilising staff and volunteers who are from the community, and ensuring that the peer-led program is seen as being a part of the community. W3 framework looks for signs of genuine and high quality engagement that ensures accurate and real-time community insights, including insights about how well the peer-led program is keeping up to speed with the community response to PrEP.

Alignment

Peer-led programs also need to pick up real-time signals about what's happening regarding PrEP in the broader sector (policy, health services, surveillance and social research). Changes in how PrEP is defined, promoted, accessed, or researched impacts on communities, and can enhance the peer-led program's own understanding of their communities. All this can affect how the peer-led programs operate in regard to PrEP; how well the policy response and sector aligns with the priorities of peer-led programs and their communities; and can provide guidance for adaptations or advocacy that may be required. W3 framework looks for signs that the program is able to gain real-time insights into policy and sector changes, and is able to apply a peer lens to identify the implications.

Adaptation

Peer practitioners (staff or volunteers) are in a unique position to notice cues and

patterns in their community, and so are able to constantly enhance and update their understanding of how their own personal experience of PrEP relates to a broader collective perspective of the community response to PrEP.

Because their community is changing in ways that are not easily predictable, peer programs often need to 'test the waters' as they adapt with their communities and monitor carefully. This includes adaptation within and across the range of peer activities, for instance, peer service delivery (such as peer-led rapid testing), peer health promotion (such as peer developed and implemented campaigns or community development), or peer leadership (such as peers taking leadership roles in their community, their sector, or participating in policy reform). This also means the organisation within which the peer activities are based need to understand the nuances of PrEP, in both the community and the policy systems, in order to support rapid adaptation. The W3 framework looks for signs that programs and organisations are learning and adapting (or even pre-empting) with their communities.

Influence

■ Within community systems

The unique opportunity peer-led programs have is that they are able to participate as a structural component within their community, rather than intervene on their community. While this still includes the usual changes in knowledge, attitudes or behaviour, it also includes the intentional and unintentional or distal influence a program has when it is navigating and participating in, rather than observing, community tensions and challenges in areas such as PrEP. W3 framework is looking for signs that: communities see the contribution of the peer-led program as culturally credible and authentic; communities are incorporating these into the ongoing adaptations in the community; and that the community expects the program to be based in the reality of their shared lives. The changes in the engagement with the peer program can be an indicator of the authenticity, relevance and impact of past influence.

■ Within policy systems

Other organisations in the policy and sector system, as they also adapt to

PrEP, can be enablers or barriers to the role of peer-led organisations. For example, the way PrEP is discussed in a clinical setting, or in the media, can reinforce or undermine strategies to reduce stigma.

Insights from peer-led programs may be the broader sector's only source of real-time knowledge about emerging issues in rapidly changing environments. For example, insights about how different networks of gay men are adapting and responding to the emerging use of PrEP are insights useful for policy and health services as well as guiding social research. W3 framework looks for signs of the quality of this participation in the policy and sector system, recognising it as a key to improving system alignment to enhance the effectiveness of peer-led programs. W3 framework recognises that if funders, policymakers and researchers are not drawing on and gaining strategic benefit and insight from peer-led programs and leadership around issues such as PrEP, then the partnership as a whole is not maximising its investments.

Relationships between functions and other system elements

The most important part of the framework is how these functions and other elements in the peer-led program's system interact with each other. The diagram of the W3 framework (Figure 1) shows the flows of influence and knowledge that are crucial for the peer program to be effective and sustainable in this environment.

For example, if engagement is not functioning effectively, then our mental models will not be up-to-date, or not complex enough, and we will not be able to adapt programs to be influential within the community or have useful insight to leverage changes in the policy system. If we do not have effective alignment then controversial programs may be vulnerable to or caught unaware of political or policy changes, without enough time to influence the policy system or adapt the peer program.

Every box and arrow on this diagram is a potential source for an indicator – a thing that we need to be confident is happening in order to feel confident that a peer-led health promotion program is effective and sustainable in the long term. The framework helps us identify and tailor the most important indicators for monitoring the long-term effectiveness and sustainability of a program.

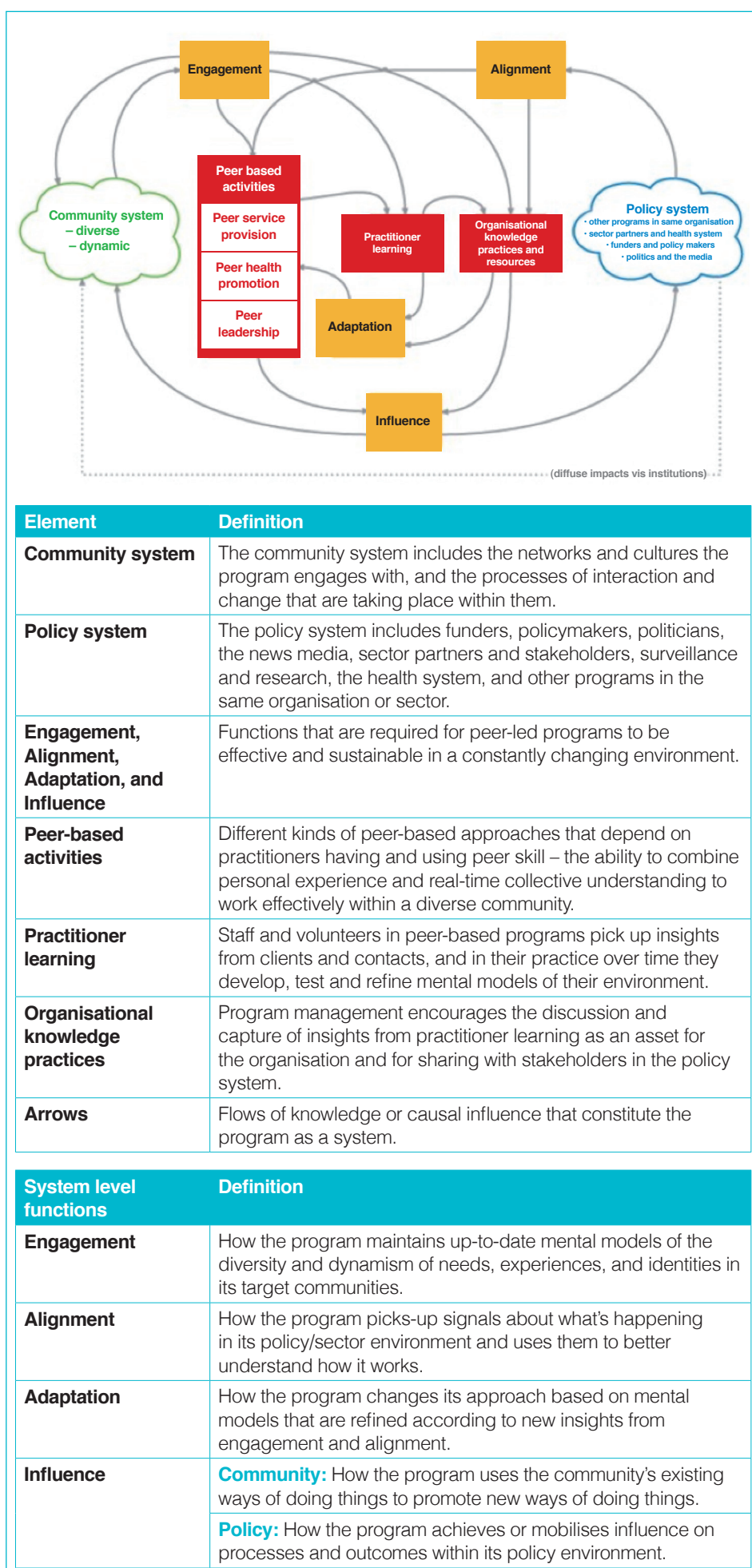


Figure 1 The W3 Framework

Piloting indicators of quality and influence in peer-led health promotion

We worked with most of the W3 project partners to develop indicators under each of the four functions. The indicators are defined as ‘things that would *be happening* if this function were being fulfilled’. Table 2 provides hypothetical examples of Quality and Influence Indicators for a peer-led program to support gay community engagement with PrEP. We piloted a range of different methods and tools for gathering insights against the indicators and functions, guided primarily by the needs of our partner agencies and the questions they wanted to answer within their community and policy systems. Our goal was to develop methods that *add value to existing practices* without creating too much additional labour. The main aim was to identify what would be feasible within the resources of community and peer-led organisations. The analysis of these tools is still underway and the results will be available soon on the W3 project website (www.w3project.org.au)

Next steps

The next phase of W3 will build on and extend this work by trialling and refining the W3 framework at an organisational level. We plan to recruit two peer-led organisations in HIV and hepatitis C to implement and trial the W3 framework across their entire organisation. This will include the development of practical and sustainable tools that use data and insights to improve the impact of programs as well as share real-time knowledge with the broader sector and policy response.

The W3 project continues its aim to support community and peer-led organisations to demonstrate their quality and impact, adapt their programs to the rapid changes occurring in HIV and hepatitis C, and strengthen the evidence base to guide investment in community and peer-led health promotion programs.

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- 2 Brown, G., Reeder, D., Dowsett, G., Ellard, J., Carman, M., Hendry, N., et al. (2015). Investigating combination HIV prevention: isolated interventions or complex system.

Table 2 Example Quality and Influence Indicators

Adaptation	<ul style="list-style-type: none"> ■ The program integrates peer insights with knowledge acquired from research, and signals from the policy system. ■ The program's mental maps of the community and policy systems and their responses to PrEP are checked and refined on an ongoing basis. ■ Organisational leadership support continual practitioner learning and facilitate the capture and packaging of knowledge from peer insights as an organisational and strategic asset. ■ The team identifies emerging practices with PrEP to assess their implications for prevention across the community.
Engagement	<ul style="list-style-type: none"> ■ Insights from on the ground peer programs update and strengthen the understanding of how PrEP is being used in the community. ■ Community members recognise the program as a participant within its networks and cultures and feel a sense of ownership around its work. ■ The program updates a mental map of the networks and cultures within the community and works to extend its reach within them. ■ Peer staff use personal experience as well as cultural knowledge to communicate and work effectively with community.
Influence	<p>Community</p> <ul style="list-style-type: none"> ■ Materials produced by health promotion undergo circulation, adaptation and incorporation by members of target networks and cultures. ■ Reach and recall of health promotion products, images or messages among members of the targeted networks and cultures. <p>Policy</p> <ul style="list-style-type: none"> ■ Policy, media and funding environment supports (or does not impede) innovative and culturally relevant approaches to expanding meanings of safe sex. ■ The broader sector and policy system includes and values the peer approach and insights it generates.
Alignment	<ul style="list-style-type: none"> ■ The team identifies emerging practices with PrEP to assess their implications for prevention across the community. ■ Other programs and sector stakeholders adapt their approach to support the effectiveness of the program. ■ The organisation communicates with sector partners to improve their understanding of the program's perspective on emerging issues. ■ The program actively seeks out and uses knowledge from partners and stakeholders with different perspectives on emerging issues within the sector.

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- Shiell, A., Hawe, P., Gold, L. (2008). Complex interventions or complex systems? Implications for health economic evaluation. *British Medical Journal*, 336(7656), 1281–1283. doi: 10.1136/bmj.39569.510521.AD
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- 5 Adam T. (2014). Advancing the application of systems thinking in health. *Health Research Policy and Systems*, 12(1), 50. doi: 10.1186/1478-4505-12-50
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Working with gay and bisexual men as cultural insiders: AFAO's approach to health promotion research

By **Dean Murphy**

Over the last ten years AFAO has led a number of research projects that have introduced theoretic, methodological and empirical innovations in the field of HIV health promotion. In this article I briefly describe four such projects that I was involved in.

Learning about sex

In 2006–07 I worked with David McInnes (from Western Sydney University) on a project that looked at the ways in which gay men learn about sex, and analysed these in terms of the different ways knowledge is produced and distributed.¹ This project, which included a workshop, report and journal article, concentrated specifically on the contrast between formal sexual health education and everyday contexts of sexual learning.

This work made an important theoretical and analytic intervention into the field of HIV prevention by applying a sociological framework articulated by the British sociologist Basil Bernstein², to a series of educational interventions developed and used in community-based programs targeting gay men. Bernstein's theory of

recontextualisation, involves an analysis of how knowledge is acquired and how it circulates. We looked specifically at the orientation of pedagogy (how knowledge is learnt, classified and framed), the mode, and the structure (whether it is horizontal or vertical³). We also looked at how pedagogy can vary in its explicitness and visibility.

Also important were the reflections on how the disposition of pedagogical subjects is an important consideration in developing formal sexual health education, including an acknowledgement that the formal education strategies that worked in the early days of the HIV epidemic may not be as effective today.

In the report we applied the same analysis to a hypothetical campaign in development, and in the workshop we held with HIV educators from around the country, we asked participants to apply it to their own – and each other's – work. Through this process we were able to show how Bernstein's analysis can be used as a reflexive exercise *during* the development of an educational intervention, rather than retrospectively.

Cultural analysis

In 2006, with Jeanne Ellard, I undertook a cultural analysis of health promotion materials to examine some of the implicit and explicit assumptions that the framing of health promotion makes about its target group (in this case, gay men) about 'responsibility' for preventing HIV transmission. Also we examined whether these framings had changed over the course of the epidemic, and if so, in what ways, and for what reasons? We analysed the language used in just over a hundred HIV education posters and advertisements that targeted gay men produced by AFAO and ACON between the years 1988 and 2006, coding these materials with a particular focus on the issue of 'responsibility' for HIV transmission.

Through this process we identified three distinct framings, which were clearly defined by the period in which they were produced. In the years 1988 to 1996, preventing HIV transmission was conceptualised as a *shared and community responsibility*.

In the immediate period after 1996, there was a shift in the language and

framing of the educational messages and these materials addressed *individual consumers* of health promotion. The final period, which emerged in the early 2000s at the time of rising HIV infections, was identifiable by HIV education messages that framed its reader a 'citizen' in the sense of being invested with both rights and responsibilities. Gay men were positioned as making choices, while also taking account of the 'other'. It might be an interesting exercise to apply the methods and approach used in this analysis to the materials produced since 2011 (i.e., since the landmark 2011 United Nations Political Declaration on HIV/AIDS).

Gay men and HIV testing

In 2012, AFAO commissioned research consultant Natalie Rowland (from redrollers) in conjunction with Penny Hagen (University of Technology, Sydney, and smallfire), to undertake exploratory research on barriers to HIV testing.⁴ The aim was to inform the development of community-based HIV testing services that were planned at the time, and also to inform communications (i.e. campaign messages) to enhance testing frequency.

The project used 'cultural probes', which are techniques used to inspire ideas about people's lives, values and thoughts. In this case, probe packs included a mapping journey (related to HIV testing), a video/ audio diary of testing experiences, and a letter-writing project (to the designer of a hypothetical new HIV testing service). This method was then followed up with online discussion groups, and two age-stratified co-design sessions.

The use of these innovative study found that there was still significant anxiety and feelings of being 'judged' in some services, which in turn led to deferring or avoiding testing. The logistics of testing were also a key barrier – finding services, booking appointments, travel and waiting time, and returning to get results.

This research elicited three concepts that needed to be attended to in service design: comfort, control and connection. To increase testing frequency the process needs to be easier and more *comfortable*, which means feeling cared for and respected, not being judged and having anxiety minimised. The concept of *control* over testing meant creating a sense of being confident, informed and in charge.

And *connection* meant establishing proximity to exactly what is needed, enhancing confidence and safety.

Notably, the innovative methods used in this project were particularly engaging for participants in the project, and the report (short version available on the AFAO website⁵) was the most requested product I have ever been associated with at AFAO. Also, AFAO has established links with the co-founder of the cultural probes method⁶, Bill Gaver (from Goldsmiths) to develop ideas for research on HIV pre-exposure prophylaxis.

A participatory peer ethnography of community-based HIV testing

The final example of innovative community-based research projects was an ethnography established to describe the key features and service-design strengths of different community-based HIV and sexually transmissible infection (STI) testing approaches. The project focused on five community-based testing sites operated by state-based AIDS councils, and used a range of ethnographic techniques including inviting peer workers to become peer ethnographers.

The peer ethnographers and were provided with training and mentorship by the consultant researcher, Dr Jeanne Ellard. These peer ethnographers then actively observed testing sessions in which they participated. Most importantly, these ethnographic techniques enabled the collection of data about how clients, clinicians and volunteers use the space, the verbal and non-verbal interactions between these different actors. The use of ethnographic research techniques (in the form of written field notes) provided valuable insights into the ways in which the use of space might be improved, and client and peer experience of the service enhanced.

The project provided important and timely findings related to the processes involved in community organisations and clinical services working together in new ways, as well as interesting variations in the understanding of what defines a peer-based testing service. Crucially, in this project, the peer ethnographers were members of the group or population being researched and active participants in the field or practice under investigation (i.e. community-based testing sites targeting

gay and bisexual men). Their position as 'cultural insiders' provided a unique access point to the *in situ* meanings, practices and interactions of everyday life in ways that would not have been feasible for an external researcher to observe without changing the clinic environment.

Looking forward

One way of increasing the impact of this kind of research, and building a body of evidence for the effectiveness of peer-based HIV prevention is to publish analyses such as these in peer-reviewed journals. Apart from research conducted on texts such as health promotion materials, the possibility of submitting manuscripts to journals requires review of a human research ethics committee registered by the National Health and Medical Research Council (NHMRC).⁷ At this time, there is no such ethics committee in the HIV community sector, meaning that research is often dependent on the participation of institutional partners in the university sector. One wonders if it might be worth investing the resources – which are significant – in establishing such a committee for AFAO and its members.

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HIV cure research: seeking an end to HIV through partnerships

By Jennifer Power and Brent Allan

In 2008, *The Wall Street Journal* ran the headline, 'A Doctor, a Mutation and a Potential Cure for AIDS'. Problematic headline aside, this article was notable for first introducing the world to 'the Berlin Patient' – Timothy Rae Brown, a man who had been 'cured' of HIV through a bone marrow transplant conducted as part of his treatment for leukaemia.^{1,2}

Brown is now widely known as the only person to have been cured of HIV, and his case is recognised as a 'game changer' in clinical research for a HIV cure.

The procedure received by Brown involved a bone marrow transplant from a donor with an exceedingly rare genetic mutation, conferring a natural resistance to HIV. The transplant was expensive and highly risky – the mortality rate for this procedure is around 20%. As such, this approach is unlikely to ever become an option for wide-scale HIV treatment.³

However, the success of Brown's treatment did raise the theoretical possibility that HIV could be curable, opening new

space for clinical and social debate about potential research directions. An increase in scientific attention and funding for HIV cure research has followed.⁴

Today there are over 100 clinical trials in progress across the world – including in Australia – relating to medical interventions that could contribute to achieving a 'cure' for HIV.⁵ However, what such a cure might look like is uncertain and many researchers suggest the term 'clinical remission' is likely to be more appropriate than 'cure'. Either way, much of this research is in the early stages. If a cure does become available it will be many years, if not decades, away.⁶

So what is the role for community in HIV cure research?

Clinical research is often seen as the domain of scientists and medical professionals – something to which non-experts, or the community more broadly, would have little to contribute. But the history of HIV challenges this. People living with HIV and 'treatment activists'

have long insisted on active involvement of people living with HIV (PLHIV) (and other 'health consumers') in rolling out new treatments, in framing biomedical research and in developing strategies to enhance the accessibility of HIV treatment.

In the US, the inaugural demonstration by ACT UP, held on Wall Street in New York City in 1987, was driven by a demand for the 'immediate release by the Federal Food and Drug Administration of drugs that might help save our lives.'⁷ This demand reflects the core basis of treatment activism – insistence on a greater role for PLHIV and community advocates in decision making about clinical issues relating to HIV, including the ethical oversight and implementation of clinical trials.

In Australia, the input of HIV-positive people has been facilitated by the partnership approach to HIV, which helped build collaborative relationships between people with HIV, the community sector, the medical profession and scientific researchers. This approach was largely unprecedented in terms of

the involvement of ‘consumers’ in the processes of clinical trials and medical decision-making more broadly. In 1993, in recognition of the tenth anniversary of the Victorian AIDS Council, the then President, Michael Bartos, wrote:

‘It may seem old hat now, but we should not forget the struggles fought around the phrase “people living with AIDS”. The resistance to a passive medicalisation of people diagnosed with AIDS was strong from the outset. The combination of media portrayal of “AIDS victims” together with a paternalistic and highly technological medical system were powerful forces against seeing people with AIDS as active agents in control of their lives. The battle fought by people living with AIDS has revolutionised the relationship between the medical system and a group of erstwhile “patients”.’⁸

So it is into this space that the new wave of HIV cure research has emerged. The scientific world has responded accordingly. Most funding bodies and major HIV research agencies have a dedicated focus on engaging communities in HIV cure research. The International AIDS Society, for example, has a program to enhance community engagement and understanding of community concerns about HIV cure research.⁹

But there are still uncertainties about the best ways for HIV-positive people and community advocates to be involved. It is one thing for medical scientists to pursue engagement and consult with communities; there also needs to be a conversation among people with HIV and within communities about HIV cure research to identify concerns, issues and strategies for being actively engaged alongside clinical researchers.

So what are community perspectives on HIV cure research?

In early 2016, a workshop was held in Victoria providing an opportunity for a range of stakeholders from the HIV sector to discuss social and ethical concerns relating to HIV cure research.

The workshop was a joint collaboration between Living Positive Victoria and the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe

University. It was held as part of a broader project that also involves collaborators from the Australian Federation of AIDS Organisations (AFAO), the National Association of People with HIV Australia, the Peter Doherty Institute for Infection and Immunity at the University of Melbourne, the University of North Carolina and Johns Hopkins University in the US.

In introducing this workshop, Brent Allan, Chief Executive Officer of Living Positive Victoria, stated: ‘We need a balance between hope and healthy scepticism’ about HIV cure research’. This emerged as a major theme throughout the workshop.

Workshop participants were keen to discuss ways to generate interest and enthusiasm about HIV cure research, including encouraging participation in clinical trials where appropriate. But there were concerns about managing false hope – particularly given media tendencies to exaggerate claims about an immanent cure.

The false hope shifts to confirmed scepticism when media representations of quality research fail to deliver on the stated claims. The obvious impact is that some people with HIV ‘hold out’ for a cure, perhaps even betting their treatment decisions on the possibility that a cure will become available soon. This potentially has a significant psychological impact – the emotional rollercoaster that comes with hopes raised, then dashed again and again.

Unrealistic expectations for a cure might lead people to volunteer for trials assuming they will receive greater ‘curative benefit’ from the trial than is likely. It is ethically important that trial participants are clear about the risks and benefits of participation. There is a balance to be struck between encouraging hope,

optimism and choice, while recognising the vulnerability of some people who are desperately searching for a cure.¹⁰

Addressing the fears, hopes, aspirations and conundrums of people with HIV requires a multi-partnered communication and education strategy involving a wide range of voices, perspectives and interpretations.

Monitoring media is important. AFAO produces a key resource to guide journalists reporting on HIV¹¹, and PLHIV advocacy agencies are well-practised at providing media commentary. However, it is important that journalists are aware of best practice, and that the HIV sector works to maintain strong relationships with media outlets and individual reporters, ensuring that people with HIV are called upon for commentary whenever new stories on new cure research arise. This is also where partnership with the scientific community comes into play: it is important to align media responses to credible sources within the scientific community, to ensure that both community and scientific voices are accurately represented.

How do we ensure the continued accurate and realistic information about HIV cure research is maintained in light of slow but continued gains? We can achieve this through information being made available on websites, through community information sessions, in newspapers and so forth.¹² But it’s the attention and commitment to explaining the complexity of cure science over the long term that must be mustered.

A ‘cure’ for HIV might mean many things. It could mean long term viral suppression without medication. It could mean total elimination of the virus. It could mean

How do we ensure the continued accurate and realistic information about HIV cure research is maintained in light of slow but continued gains? We can achieve this through information being made available on websites, through community information sessions, in newspapers and so forth. But it’s the attention and commitment to explaining the complexity of cure science over the long term that must be mustered.

something else again. At this point in time, what a 'cure' for HIV might look like is not entirely clear.

As we evolve community understanding about an HIV 'cure', we need to encourage a critical and sophisticated approach to appreciating the complexity of information about cure research. Use of terms such as 'remission' or 'long term viral suppression' rather than 'cure' may encourage more careful thinking about what a cure might actually mean for people with HIV. It might also help manage expectations and expand understanding of the complexities of HIV cure science.

Perhaps we need to bust apart the term 'HIV cure' into its various manifestations so we can re-orient the discussion.

The priority is obvious. We must invest in building literacy about HIV cure among people with HIV and the community more broadly. This will help people understand more about the likely outcomes of cure research and ensure people interested in trial participation have access to reliable information to help guide their decisions.

Information provision is also about equity. Equity concerns were raised a number of times throughout the workshop. It was recognised that, while many HIV-positive people are highly educated and well-connected into PLHIV networks and information sources, many are not. Women and heterosexual men, for example, may be less connected to the HIV sector. Newly diagnosed people with HIV may be vulnerable to misinformation and have less experience dealing with the medical system. PLHIV from culturally and linguistically diverse communities and newly arrived migrants may have less capacity to access or understand health education resources or to connect with other people with HIV or the HIV sector.

Our commitment to the provision of information on cure research needs to be generated with equity concerns in mind and it requires the old adage of knowledge provision plus changing attitudes occurs most effectively over time and must include clinicians and other direct service providers.

As one workshop participant said, 'It is important for advocates and the sector to advance and promote the interests of

people who may not have the capacity to advocate their own needs'.

So where to from here

The workshop closed with a screening of the closing scene from the 1990 film *Longtime Companion*.¹³ In this scene, underscored by the beautiful Zane Campbell song *Post-mortem Bar*, three friends (John, Fuzzy and Lisa) walk along a beach reflecting on the loss of their friends and lovers to AIDS.

John says, 'I want to be there, if they ever do find a cure'.

Fuzzy replies, 'Imagine what it would be like,' to which Lisa aptly responds, 'Like the end of WWII'.

Campbell's lyrics follow on, 'And we'll go down to the post-mortem bar and catch up on the years that have passed between us and we'll tell our stories', while we watch Lisa, Fuzzy and John imagine seeing their friends again in a joyful (post-war) celebration.

A cure for HIV is the ultimate (and long-awaited) goal. This is what makes the renewed focus on HIV cure research so meaningful and important.

But the HIV 'cure' – and cure research at any stage – is not just about science as history has shown us. Irrespective of whether or not a HIV 'cure' ever becomes available, this research will have an impact on people's lives. The people most affected need to be informed so they can have a say about how this plays out and so that balance between optimism and healthy scepticism can be realistically managed.

Perhaps, like the end of WWII, the collaborative partnership between the allies in the response – people with HIV, the HIV sector and the scientific community will create the momentum needed to ensure we are all fighting the same fight, with the same goals and the same mission in mind.

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The HIV prevention revolution: measuring outcomes and maximising effectiveness in NSW

By **Phillip Keen, Christine Selvey and Andrew Grulich**, on behalf of the investigators on the HIV prevention revolution, measuring outcomes and maximising effectiveness NHMRC Partnership Grant and the project steering committee.*

Five years ago, the prospect of ‘ending HIV’ would have been considered a fantasy. Due to extraordinary biomedical advances in HIV prevention, today this goal is not only considered achievable, it is the subject of a major public health initiative between government, the community and researchers.

We know now that early HIV treatment has tangible health benefits for people with HIV, as well as dramatically reducing the likelihood of onward transmission.^{1,2} We also have overwhelming evidence that pre-exposure prophylaxis (PrEP) works^{3,4,5}, and we are operating in an environment where recent regulatory changes are making it easier for Australians to access HIV testing. All this means that, for the first time ever, we have a real opportunity to turn the HIV epidemic in this country around.⁶

In parallel to these recent advances, improvements in data collection systems are enabling key data to be more easily captured, improving monitoring and evaluation activities, while ensuring that the privacy of individuals is maintained.

Introduction

A primary goal of the *NSW HIV Strategy 2016–2020*⁷ (the Strategy) is to virtually

eliminate HIV transmission in NSW by 2020. A five-year National Health and Medical Research Council (NHMRC)-funded partnership project has been established to enhance monitoring and evaluation of the Strategy. The major partners in the study are NSW Health and the Kirby Institute, working alongside the Centre for Social Research in Health (CSRH), ACON, Positive Life NSW, and ASHM (Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine).

The aim of the research is to optimise the implementation and rollout of new biomedical approaches to HIV, while ensuring that ‘traditional’ HIV prevention approaches are maintained and that program characteristics contributing to successful outcomes are identified.

The implementation research will be based on optimising the delivery of four key ‘pillars’ of HIV prevention (Figure 1), namely:

- 1) increasing HIV testing
- 2) increasing HIV treatment
- 3) maintaining or increasing safe sexual behaviour, and
- 4) identifying the ‘best fit’ for the positioning of pre-exposure prophylaxis (PrEP) in the HIV response.

Data collection and reporting systems are being developed in each of the four pillars to monitor the implementation the effectiveness of strategy implementation, identify predictors of successful uptake, and to provide feedback to program coordinators so that ongoing adjustments and improvements can be made.

In each of the four pillars, the project will determine consumer, clinical and other factors which predict successful uptake. The project will also assess whether there are unintended negative consequences of the implementation of new prevention strategies, and develop a sustainable framework for ongoing evaluation of the population impact of the Strategy.

Governance structure

The Project commenced in January 2015. Each of the four project pillars has a working group, overseen by co-chairs from the Kirby Institute and NSW Health. The working groups include representatives from partner organisations and other key organisations, with coordination support from research officers based at the Kirby Institute. The working groups provide advice on the development and implementation of the research plan, and regular progress reports are provided to the

Project Steering Committee. The Steering committee is comprised of representatives of all project partner organisations, and provides strategic advice on research directions and new and emerging trends in HIV prevention to an existing NSW HIV Strategy Implementation Committee.

Research plan

The focus of research in the project is to develop, standardise and expand data collection mechanisms and to create a comprehensive, rigorous, overarching monitoring and evaluation structure which enables rapid feedback to guide policy and to identify gaps in the prevention response.

HIV testing

Work is underway in the HIV testing pillar to review data available from current Ministry of Health data collection systems, and to expand and enhance data collection from clinics and laboratories in order to support more sophisticated and timely analysis of HIV testing data.

We are drawing on data from NSW sites in the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance of STIs (ACCESS) system (a collaboration between the Kirby Institute, Burnet Institute, National Reference Laboratory and participating sites), to develop a real-time reporting framework.

As of April 2016, the ACCESS network in NSW includes 36 sexual health clinics, six private general practice clinics with medium and high caseloads of gay and bisexual men (GBM), four community-based HIV testing services, three major hospital-based HIV and immunology clinics, and seven public and private pathology laboratories. This system will capture the bulk of HIV testing data (and HIV treatment and viral load data, see below) in NSW from public and private clinics. Through the use of 'GRHANITE' software, which extracts and links records from different clinics in real-time, we have developed five additional quarterly testing indicators to complement the existing NSW data reports. These include:

1. Proportion of people tested at least once for HIV in the previous year
2. Average number of HIV tests per person, per year
3. Proportion of GBM tested for HIV with a previous HIV test in the past 6 and 12 months

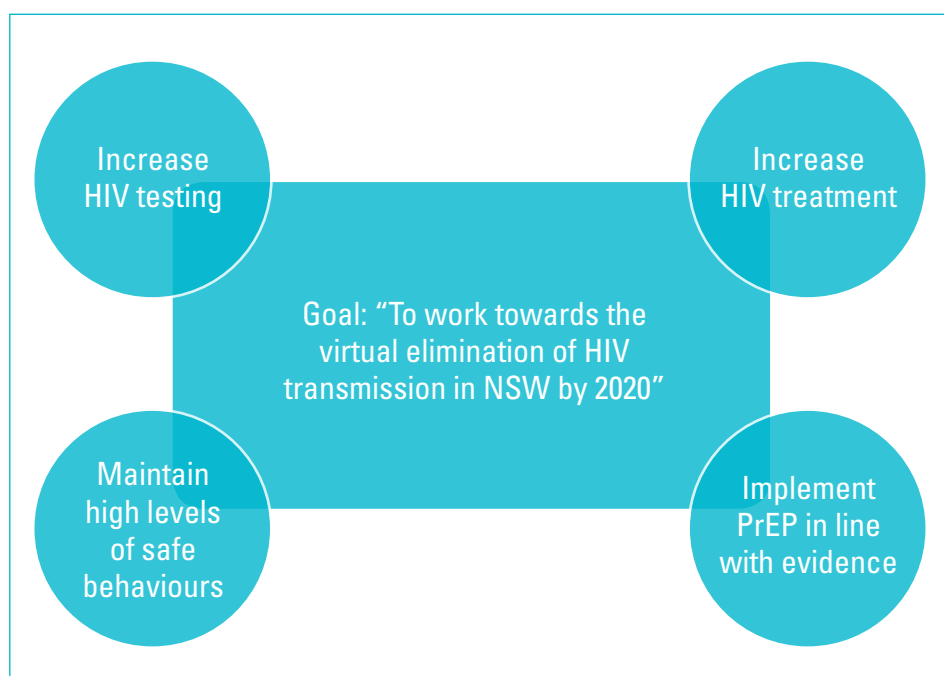


Figure 1

4. Proportion of people who received an HIV test within one month of a diagnosis of a sexually transmissible infection (STI)
5. Proportion of tested for HIV with a positive result (HIV positivity).

Through the creation of a large cohort of GBM in NSW we will be able to measure HIV incidence among GBM.

All the indicators will be stratified by service type, risk, age group and priority population. The aim of the quarterly reports is to assess whether new initiatives have reached the intended target population, and led to an increase in testing and detection of infections. On an annual basis we will assess changes over time, and identify patient and service level factors that predict repeat HIV testing.

HIV treatment

The HIV treatment pillar includes a number of key projects.

The 'HIV treatment and care cascade' has become the international standard for describing the uptake of HIV diagnosis and treatment.⁸ We continue to develop enhanced data collection and analysis systems at the NSW Ministry of Health, and through the expansion of the ACCESS network (described above), to develop more accurate measures for use in reporting on the Cascade, and to monitor changes over time. This analysis will be used to assess the impact of the Strategy.

These enhancements are listed below:

- a. **Measurement of undiagnosed infection:** The 2014 COUNT study, led by Associate Professor Martin Holt of the Centre for Social Research in Health, estimated that the proportion of GBM with HIV who are undiagnosed in NSW is 10.8%.⁹ We shall repeat the COUNT study in 2018 to ensure we have an accurate measure of the undiagnosed population to inform the first step of the Cascade, and to see if the intensification of prevention, testing and treatment in the current Strategy has resulted in a decline in undiagnosed HIV.
- b. **Estimation of people living with HIV:** To gain a more accurate measure of the number of people living with HIV in NSW who are diagnosed, we will perform data linkage of the HIV register with the death register, and to identify people who have migrated from NSW, we will undertake active follow-up (via the diagnosing doctor) of people diagnosed during the last five years.
- c. **Estimation of care:** To improve our measures of the proportion of people retained in care, the proportion receiving HIV antiretroviral treatment and the proportion with an undetectable viral load, we will use data from the expanded ACCESS network and new systems currently being developed to extract data from public and private clinics providing care to people living with HIV.

HIV phylogenetic clustering

To determine the population level contribution to ongoing HIV transmission of those who are in very early stages of HIV infection, when levels of infectiousness are highest, we will undertake annual analyses of HIV phylogenetic clustering. This sub-study will utilise laboratory data already collected through routine testing for antiretroviral treatment resistance. To help guide investment in HIV testing programs, linkage with the NSW HIV register will be used to estimate the proportion of transmissions from people with early infection. The data will also provide information about the effect of the various prevention interventions on the rate of growth of transmission clusters and their make-up, indicating where the strategies have been effective and where they require more focus. Data on transmitted viral resistance in NSW will guide recommendations on very early HIV treatment.

Maintain safe behaviour

In the context of the success of HIV treatments and PrEP in reducing the risk of HIV transmission during condomless sex, we need new measures to assess behaviour in which HIV transmission risk is elevated. We have developed new measures to identify practices where the risk of sexual transmission is greatest, i.e. receptive condomless anal intercourse by men who are not on PrEP, and involving partners of unknown HIV status or detectable HIV viral load.

We will conduct a program of research to monitor and understand the key behavioural indicators that underpin the Strategy, including the new measures described above, and knowledge and attitudes regarding each of the four pillars of the Strategy (HIV testing, HIV treatment, safe behaviour and PrEP). Given the central role of HIV disclosure, we will conduct quantitative online surveys to investigate the dynamics and contexts of HIV status disclosure, followed by qualitative research using in-depth interviews to assess how serostatus is disclosed and understood.

We will also assess methods of recruiting GBM who engage in high risk sexual behaviour with no evidence of risk reduction, to better understand the motivations and circumstances of their risk behaviour.

PrEP

Work has commenced on three inter-related projects to help define the role of PrEP within the new HIV prevention environment. First, the NSW Partnership Project supports work on measuring adherence in the NSW Health-funded PrEP demonstration study, PrELUDE. Specifically, we measure adherence to PrEP in a sub-study of 100 PrELUDE participants who provide blood samples, which are collected, processed and stored at three internals, and then shipped for analysis at the Johns Hopkins University. Adherence is measured by blood levels of Truvada components in blood plasma and peripheral blood mononuclear cells (PBMCs). Project findings are expected to inform support interventions for optimal PrEP delivery approaches in 2017. Secondly, we are investigating the set-up of systems to monitor PrEP prescriptions in NSW and the effect of PrEP use on HIV incidence, especially in the context of large-scale access to PrEP. Thirdly, we will investigate the effects of PrEP use on risk behaviour. Additionally, from 2016 to 2019, we will conduct annual assessments of PrEP awareness and uptake using available data sources.

Conclusion

Over the 2015–2019 period, a coordinated Strategy-led process is occurring in NSW to dramatically reduce new HIV infections. This research will enable a detailed assessment of the success and failures of this approach, and the reorientation of prevention responses in the state. The new knowledge about HIV prevention that will arise from this research will have a direct impact on program delivery in Australia and in other high income settings.

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Breaking the awkward barrier with #ComePrEPd: a community-led HIV prevention campaign

By Robert Muscolino

Background

Rising rates of HIV notifications in Queensland and increasing discussions within the gay community about pre-exposure prophylaxis (PrEP) provided the context for the development of Queensland AIDS Council's #ComePrEPd campaign, a community-driven initiative aimed at raising awareness about PrEP and HIV prevention among gay men and other men who have sex with men.

In 2014, there were 365 notifications of HIV in Queensland, 245 of which were new diagnoses. Of these cases, 222 were among men, which was an increase on the previous year's total of 164. These figures reflected a 50% increase in new HIV diagnoses among men who reported having sex with men and/or were bisexual, though the proportion of total new

Table 1 Number and rate per 100,000 population of new diagnoses in Queensland, 1 January 2010 to 21 December 2014*

		2010	2011	2012	2013	2014
New diagnoses in Queensland		204	194	206	181	245
	Rate	4.5	4.3	4.5	3.9	5.3
First diagnosed in Queensland		36	29	55	59	62
	Rate	0.8	0.7	1.2	1.3	1.3

* Excluding those first diagnosed in another Australian state or territory.
Source: 2014 Queensland Gay Community Periodic Survey.

diagnoses was comparable to the four-year average (Table 1).¹

The 2014 Queensland Gay Community Periodic Survey confirmed an increase in non-condom based risk reduction strategies and a significant increase in unprotected anal intercourse with casual partners since 2010.

At the same time, discussions about PrEP were becoming more commonplace within the gay community. Speculation

about the effectiveness of this new HIV prevention method among many gay men was rife, despite an increasing body of scientific research indicating that PrEP is indeed a very effective HIV prevention method. Discussions about PrEP were further fuelled by the emergence of online importation options at a time when Therapeutic Goods Administration (TGA) approval of Truvada® for HIV prevention seemed uncertain, or at the least, a long way off.

Breaking the awkward barrier

In response to all this, in July 2014 the Queensland AIDS Council Board (QuAC) board decided to develop a community-led PrEP awareness campaign – a first for Australia. A community consultation group was formed to lead the development of a campaign.

The group initiated fortnightly meetings at QuAC's head office in Brisbane, where diverse members from Queensland's lesbian, gay, bisexual, transgender and intersex (LGBTI) community were invited to provide input into what a PrEP awareness campaign for gay men might look like. These meetings soon expanded to include community members from across the country via telephone and Skype. As part of the community consultation process, a Facebook group was set up to provide another avenue for community input into the look and feel of the campaign.

Through this process, a number of key themes began to emerge. The community wanted an awareness campaign that was sex positive, gay affirming and contained a humorous tone. Importantly, the community expressed a desire for a campaign that was clearly owned and created by gay men, for gay men, prompting a decision not to engage external advertising agencies in the development and rollout of the campaign and messaging. This 100% community-led approach continues to drive the campaign that became known as '#ComePrEPd'.

Campaign launch

At the invitation of the Australian Federation of AIDS Organisations (AFAO), #ComePrEPd was formally launched at AFAO's Community and Advocacy Hub at the Australasian HIV & AIDS Conference in Brisbane, September 2015.

QuAC's executive director, Michael Scott, health promotion officers Robert Muscolino (Brisbane) and Alex Bartzis (Cairns) along with the campaign's creative director Dou Ribu and video/web and graphic designer, Dale Napier, all spoke at the launch, discussing the campaign's inception, goals, community-led design and tone. This discussion was followed by a panel of Brisbane community members who shared their personal stories about accessing and taking PrEP.



Pictured top: #ComePrEPd campaign banner, and **above:** #ComePrEPd launch at the AFAO Community and Advocacy Hub, Australasian HIV & AIDS Conference, Brisbane, 17 September 2015. Photo: © Australasian HIV/AIDS Conference, ASHM, and Amanda James of James Photography Services. Reproduced with permission.

At the launch, the campaign website (www.comeprepd.info) and Facebook page were also unveiled. Subsequent launch events for #ComePrEPd have occurred at community events, including the Brisbane Lesbian and Gay Pride Festival at New Farm Park, Glitter Festival on the Gold Coast and at Cairns Tropical Mardi Gras.

Campaign elements

Social media

Social media is a vital component of the #ComePrEPd campaign. There are two campaign Facebook pages, #ComePrEPd share your thoughts here and the #ComePrEPd official page. An Instagram account @ComePrEPd is also live, for use primarily at community events. To date, the campaign has more than 600 followers across the social media spectrum.

Social media provides the platform for the release of the campaign's video skits, while #ComePrEPd share your thoughts here continues to act as an important conduit for community members to provide input into the ongoing development of the campaign.

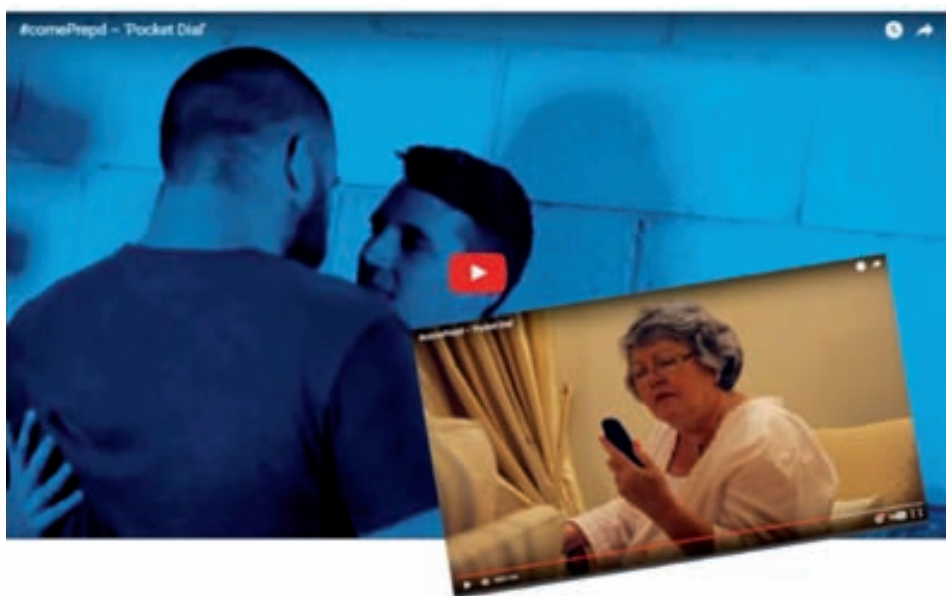
Videos

In keeping with the campaign's humorous tone, a series of 30-second videos skits were also developed, framed around the campaign's central message: 'It's less awkward to #ComePrEPd'. The videos depict awkward moments from gay men's sexual experiences, and are designed to be shared via social media to drive visitors to the campaign website.

The first of these three videos was *Pocket Dial*, which shows an awkward, late night hook-up, where a gay man accidentally 'butt dials' his grandmother during sex (his Nan is played by PFLAG's national spokesperson, Shelley Argent). The video was a huge success, attracting 2,400 views via the #ComePrEPd Facebook page, mostly as a result of community sharing.

Three more short video skits – *Breakfast Table*, *Turbulence* and *Cab Journey* – were released at the AFAO Gay Men's Health Promotion Conference in April 2016, with a further six videos in this series planned for release throughout the remainder of the year.

Shelly Argent also conducted a series of video interviews with five local gay men. Two hours of filming at a local gay venue,



Pocket Dial video screenshot, released March 2016.



A behind-the-scenes still from the #ComePrEPd video skit, *Housemate Is Out*, released June 2016.



Awkward Talk interviews, filmed at the Wickham Hotel.

the Wickham Hotel, captured a series of candid video interviews discussing real-life stories about sex and often awkward sexual encounters.

The #ComePrEPd video skits and *Awkward Talk* interviews aim to project a consistent, sex positive and humorous tone, which aim to draw people to the #ComePrEPd website by stimulating curiosity and engagement in the campaign. It's important to note that the videos do not directly mention PrEP, HIV or contain overt health promotion messaging. This approach was a direct response to feedback from our community and sector consultations, and is an important way of ensuring that the campaign stands out from other PrEP campaigns. This approach also helps address 'health promotion fatigue' among the target audience.

Website

The videos are only a small part of the information available on the #ComePrEPd website. The website is designed as a comprehensive information portal where gay men can learn all about PrEP and HIV prevention, including information about how to access PrEP.

The website includes guidance on importing generic Truvada for use as PrEP and information to how to obtain a prescription, with links to online pharmacy access points and Therapeutic Goods Administration (TGA) rules

about personal importation. The website also links to ASHM's Australian PrEP guidelines and information on the PrEPaccessNow low income support scheme.² Free downloadable access sheets outline a step-by-step process to order non-branded Truvada (PrEP), with the assistance of an informed PrEP prescriber.

The #ComePrEPd PrEP Prescriber Directory was launched in September 2015, coinciding with the announcement that QuAC was making PrEP available through its sexual health service 'Clinic 30' in Brisbane. The directory connects the community with medical practitioners throughout Queensland who are experienced in prescribing PrEP and are known to be 'LGBTI-friendly'. Details of practitioners in other states will also soon be added to the directory.

Other website content includes FAQs, basic PrEP information, links to PrEP studies, and information about how to register for the upcoming Queensland PrEP demonstration project.

The website also includes real-life stories from individuals currently using PrEP. To date, six community members have shared their experiences, discussing themes such as reduction in anxiety relating to sex after PrEP commencement, PrEP access, the experience, or lack of side effects, and PrEP stigma in the LGBTI and wider community. #ComePrEPd welcomes additional stories from other community

members who would like to share their unique PrEP experiences, in keeping with the campaign's strong focus on community input into the campaign.

Acknowledgement

QuAC acknowledges all the Brisbane community members who volunteered and provided valuable input to making #ComePrEPd possible.

To become a part of the campaign, community members are invited to share their own stories about PrEP, or to volunteer or show support for the campaign by visiting the campaign's online shop to purchase a #ComePrEPd muscle shirt or T-shirt. For more information visit the campaign website www.comeprepd.info or contact QuAC by calling 07 3017 1777.

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Building the evidence base and influencing change: examining the benefits to women living with HIV of a community-led research project

By Alison Boughey, Autumn Pierce, Heather Mugwagwa and Kathleen Azueta

This article examines the drivers of Positive Women Victoria's engagement in collaborative research and outlines an example of a small piece of research we are currently leading. We discuss the potential benefits for women living with HIV of our involvement in community-based research and some of the benefits already evident for our organisation.

Introduction

Positive Women Victoria is Australia's only community organisation specifically funded to provide support, advocacy and information to women living with HIV. For the last 25 years, we have worked successfully to address the needs of hundreds of women and girls living with HIV in a constantly evolving environment.

While historically our ability to collect and store data about HIV-positive women in Australia has been constrained, we have recently implemented secure data collection and storage systems and policies enabling us to safely collect and store information, and to use this as evidence to better inform our peer support, advocacy and health promotion activities. As a result, Positive Women Victoria now holds what is arguably the most comprehensive database of women living with HIV in Australia.

The information we have collected highlights the wide variation in women's

needs, experiences and preferences. This knowledge provides us with exciting opportunities to extend the scope of our current activities, enabling us to identify demographic trends and gaps in access to and uptake of HIV services by women. Importantly, this data further illuminates the need to apply a gendered lens at all levels of the HIV response.

To influence change, we know that we must present the evidence we hold within a framework that will lend it greater legitimacy in the scientific and policy arenas. By working collaboratively with community, clinical, educational and research organisations, we capitalise on their diverse expertise. We are ensuring we can do this in a way that meets best practice, to build a broader understanding of the systemic inequities that disadvantage and disenfranchise women living with HIV.

By piecing together a more complete picture of women's lived HIV experience, and subjecting this narrative to rigorous

analysis in the context of well-designed research studies, we will be better able to identify and fill the significant gaps in what is available to women living with HIV. This will enable us to use our position as the leading women's HIV support agency in Australia to make meaningful contributions to the broader HIV sector, and initiate effective change for all women living with HIV.

With these aims in sight, Positive Women is currently leading a small research project in partnership with the Burnet Institute, Melbourne Sexual Health Centre, and the Multicultural Centre for Women's Health. Further details are in the case study at the end of this article.

Why community-led research benefits women

Comprising around ten percent of the Australian population of people living with HIV, HIV-positive women are often described as a marginalised group within a marginalised group. Despite being a subgroup of seven of the eight priority populations identified in the Seventh National HIV Strategy¹, women are not recognised as a priority population in their own right. This lack of 'priority' status, means that HIV-positive women in Australia are under-represented, both in the response to the epidemic and in epidemiological and social research.

Women living with HIV experience gender-related disparities over and above the stigma and discrimination routinely experienced by HIV-positive people. However the biological, structural and cultural factors at the root of these disparities are not recognised in our coordinated national response to the HIV epidemic. The modes of HIV transmission, biological susceptibility, geographical accessibility, socioeconomic status, testing patterns, service use, health seeking behaviours, perceptions of risk and attitudes towards treatment are so markedly different for women than for men, that we are almost talking about a different epidemic.² These known differences in the experiences of men and women demand research that examines the unique experiences of women living with HIV.

For women from culturally and linguistically diverse backgrounds, the need for deeper understanding and greater visibility is even more critical. These women comprised around 50% of new HIV diagnoses in Victoria in 2014³ and current immigration policies and trends suggest that this proportion is likely to increase. Only around 20% of women who are currently receiving services from Positive Women are from culturally and linguistically diverse (CALD) backgrounds, with about 10% of this cohort coming from sub-Saharan Africa. This under-representation of women from CALD backgrounds in service data is not unique to our organisation or to the state of Victoria. The research project we are proposing is aimed specifically at enhancing our understanding of this group of women. This is an essential goal if we are to truly claim that we provide support and advocacy to all women living with HIV.

Benefits from engaging in research

In a constantly changing environment, competing demands make it difficult for small community organisations to engage in research; however, we know that we must follow the evidence or risk becoming obsolete. Like many organisations in the community sector, continuing to do 'what we have always done' is no longer an option. Although we are only new to this area, as an organisation we have already experienced a number of benefits to the approach:

Case study: Needs of women from African diaspora communities living with HIV in Victoria, Australia

Rationale

Little research has been conducted on the needs of African women living with HIV in Australia, or on their patterns of accessing and using HIV community support services. This may be partly due to difficulty attracting funding for research focused on women, given it is less likely to significantly impact the HIV epidemic on a larger scale. Often, migrant women's vulnerability is exacerbated by socio-cultural obstacles including language barriers in host countries. Their stories become buried, especially since women in Australia are not named as a priority population in their own right in the nationally led HIV response.

This study aims to address the specific needs of women from African diaspora communities living with HIV in Victoria. The following research question will guide the proposed study:

What are some of the structural and cultural barriers to accessing HIV community and support organisations that African-born women living with HIV face while living in Victoria, Australia?

The research project will be led by Positive Women Victoria and conducted in collaboration with our partners including: Alfred Health, Melbourne Sexual Health Centre, University of Melbourne, Burnet Institute, and the Multicultural Centre for Women's Health. Each of these partners will bring their expertise, insight, guidance, and advice on all aspects of the project from design, to ethics approval, implementation, data analysis and presentation of the findings.

In so doing, the study will further explore women's experiences of discrimination within their cultural community, as well as within the wider Australian community.

A qualitative approach involving two phases will be adopted. In the first phase, semi-structured interviews will be conducted with African women living with HIV in Australia, exploring themes such as HIV disclosure, reasons for seeking support, sources of support, barriers to support services, perception of self-perceived risk and gender inequality.

In the second phase, counsellors, social workers, service providers and clinicians who deliver support services to African women living with HIV in Australia will be invited to share their own perspectives on challenges in addressing these women's needs. The data obtained from each phase will be analysed thematically.

Planned outcomes

Findings will inform HIV community organisations to better address the needs of women, particularly women from African communities. These findings will identify the structural and socio-cultural barriers that hinder them from accessing organisations that provide support. It is imperative that this knowledge is integrated into organisations' peer support and outreach programs. Importantly, the study will demonstrate the value of engaging women as participants in HIV social research in Australia. It will also provide stronger foundations for evidence-based activism and provide evidence to support Positive Women's ongoing advocacy efforts to include women as a priority population in the Eighth National HIV Strategy.

■ **Building collaborations:** Conducting high quality social research requires us to tap into the knowledge, experience and resources of other organisations. We are fortunate to have strong relationships with partner organisations who have been more than willing to support and work with us on a range of projects. Each project

we collaborate on strengthens our relationships with other organisations equally invested in improving the lives of women living with HIV.

■ **Improved focus on data security:** Safeguarding sensitive client data is essential in maintaining stakeholder trust and protecting organisational reputation. Engagement with

research has required us to examine our IT systems, our privacy and confidentiality policies and our compliance with relevant privacy legislation. This has led to the introduction of new intake forms and the active pursuit of permission to collect and store relevant personal information. It has made us consider the purpose behind collecting and storing personal information and be certain that we are communicating this effectively to the women who seek our services.

- **Improved cultural awareness and sensitivity:** Through development of an approach that meets the rigorous requirements for Human Research Ethics Committee (HRECs) approval, organisational processes need to be reviewed and improved. Our involvement in this process has encouraged us to consider reviewing our processes for use of interpreter services as well as assess the need for cultural awareness training for staff.
- **Increasing organisational capacity:** On the ground, there are more subtle benefits brought about by fostering a culture of collaboration, such as increased organisational capacity. The hard skills required to design,

implement and manage research and evaluation projects coupled with cross-cultural, adaptive soft skills has presented opportunities to upskill staff. Honing staff skills to collect meaningful data and analyse that data through a gender and diversity lens has the potential to significantly enhance the way we deliver our services.

- **Claiming a seat at the 'grown ups' table:** Without evidence acquired through robust, collaborative research approaches, our capacity to influence meaningful change for women living with HIV is limited. Unless we are in a position to make new and unique contributions to the body of knowledge around HIV, we can find ourselves sidelined in the forums that really matter; present as observers but without sufficient legitimacy to enable meaningful participation.

Conclusion

An evidence-based approach is essential to effective health promotion and advocacy. Without data, the health needs of marginalised groups are not highlighted or fully understood. For women living with HIV, the only way to address the gaps in knowledge and influence the current

HIV data-policy interdependency is to introduce new evidence. As it stands, in the eyes of policymakers, without evidence that suggests otherwise, there is no problem – so there is no requirement for action. Through community-based research, we can align the needs of women and the priorities of researchers to put women on the agenda at a policy level.

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Criminal Law in clinical settings: guarding against the big chill

By **Sally Cameron**

It's an uncomfortable space, the murky area where HIV, clinical practice and criminal law intersect. Nowhere is that more evident than in the very guarded acknowledgment in the Seventh National HIV Strategy's guiding principles. Loath to commit, the Strategy states, 'it could be argued that criminalisation perpetuates the isolation and marginalisation of priority populations and limits their ability to seek information, support and health care'¹. Still, that's an improvement on the previous strategy which barely acknowledged the issue at all.

There is enough anecdotal and academically rigorous international research to demonstrate a direct relationship between the criminal

justice system and HIV healthcare², with the body of research having grown substantially over the last few years³. Recent examples include Lee's US study (application of criminal laws negatively impacts HIV testing rates among those most at risk of infection⁴) and Phillips and Schembri's work in England and Wales (people with HIV could not accurately describe their legal obligations despite having been counselled at the time of diagnosis)⁵.

In Australia, research on the intersection of criminal law and the HIV healthcare system is more limited. We do know that prosecutions undermine some patients' trust and willingness to speak openly to health care providers. The HIV

Futures Seven survey found almost a third (30%) of the 1,000 people with HIV surveyed were worried about disclosing their sexual practices to service providers 'because of the law'⁶. Clinical staff also report avoidance of health services following high profile HIV trials. For example, media coverage of the 2008 prosecution of an ACT HIV-positive sex worker was immediately followed by a startling drop in sexual health testing by sex workers at the ACT Sex Workers Outreach Project, falling from an average of 30 to less than two a fortnight⁷.

While more Australian research on the impact of criminal laws on HIV health seeking behaviours would be warmly welcomed, the most immediate gap in

our evidence base relates to how (or whether) criminal laws impact the work of Australian healthcare providers. That gap is hardly surprising given healthcare providers are rarely policy analysts or social researchers. Being a doctor or nurse is pretty much a full-time job, with healthcare providers primarily focused on patient care. Our lack of understanding of ways in which criminalisation may shape clinical practice, healthcare services and HIV prevention efforts enacted in the clinic means we are not able to define the problem, let alone design strategies to address it.

Early investigations of the impact of HIV criminalisation on HIV healthcare (in Canada, where prosecutions are more frequent) found that HIV health service providers were often uncertain how to discuss criminalisation, an issue which consequently undermined their clinical practice. Moreover, legal concerns eroded patients' trust in HIV and health services^{8,9,10}.

A number of recent studies in the UK, US and Canada have provided more evidence, finding that HIV criminalisation:

- **May trigger a focus on 'the law' that damages the provision of health information.**

Sander's 2014 Canadian study found HIV criminalisation negatively impacts nursing practice as public health nurses try to control information about the limits of confidentiality at the outset of HIV post-test counselling. Individual practice varies as nurses pragmatically balanced ethical and professional concerns. Some intentionally withheld information about the risk of medical records being subpoenaed, while others talked to clients about confidentiality in ways that focused on the risk of harm associated with criminalisation.¹¹

- **Undermines the therapeutic relationship between patients and counsellors.**

French's US study found that HIV criminalisation made disclosure counselling difficult, potentially compromising trust between healthcare workers and patients. Counsellors' understanding of the up-to-date science of HIV transmission risk conflicted with the need to tell clients to disclose their HIV status before any kind of sex to avoid prosecution – even when condoms are used or they have a low viral load. The study concluded that it was not only difficult for counsellors to determine when to discuss legal obligations during the counselling process, but exactly how to discuss these obligations without undermining therapeutic relationships.¹² Those assertions are reminiscent of Mykhalovskiy et al.'s earlier findings that criminal law created 'a chill' in counselling relationships – restricting or limiting open dialogue.¹³

- **May lead to medical staff providing misleading 'legal' information.**

Dodds et al.'s study of healthcare providers in England and Wales found that at times, participants' understanding of the law was guided more by a sense of morality than by a technical understanding of the law: 'Their comfort with harm reduction (as opposed to risk elimination) influenced how they advised people with HIV about avoiding criminal liability.'¹⁴ (This was also reflected in Mykhalovskiy's 2011 study¹⁵.) Others said that they avoided addressing the issue or minimised the amount of detail because they lacked confidence in their capacity to talk knowledgeably about the law.¹⁶

- **May lead to incomplete or inaccurate record taking.**

A second Canadian analysis by Sanders found that public health nurses' counselling practices prioritising client care and risk reduction were in conflict with HIV criminalisation. The anticipation that medical and public health records could be used as evidence in court influenced public health nurses' reasoning and documentary practices during HIV post-test counselling. Some documented more, while others documented less. Nurses expressed real concerns that notes could be misinterpreted and ascribed a legal significance contrary to their original purpose.¹⁷ This echoes similar accounts recorded in O'Bryne and Gagnon's 2012 study, where nurses identified this issue as new to HIV nursing:

*'Do you document or you don't? You know, I never asked myself that question before.'*¹⁸

Similarly, Dodds et al.'s qualitative interviews with HIV service providers in England and Wales found awareness of criminal trials had contributed to some clinicians changing their note-taking practices, some making more detailed notes, including those thinking that more detailed notes may be useful for a client's defence (should the eventuality ever occur); others, particularly those working in community organisations, were more likely to document less:

*'If I am working with a person who has high risk behaviour I do not document it in detail, just in case further down the line there is someone with a warrant.'*¹⁹

The voice of healthcare providers

Healthcare providers are notoriously cautious about engaging the HIV criminalisation space, however, when they do, their voice can be powerful. US physician, Dr Wendy Armstrong's first person account of the prosecution of one of her patients is a rare published work about HIV criminalisation by a practising HIV medical practitioner. Dr Armstrong relates her experience, which begins with the treatment of her patient over several years, including working through his specific issues with treatment adherence.

Healthcare providers are notoriously cautious about engaging the HIV criminalisation space, however, when they do, their voice can be powerful. US physician, Dr Wendy Armstrong's first person account of the prosecution of one of her patients is a rare published work about HIV criminalisation by a practising HIV medical practitioner.

It describes Dr Armstrong's involvement with the patient within the safety of her office 'where patients could talk frankly ... about their fears and joys, about their personal lives and sexual practices, their bodies and their symptoms'. The sanctity of that space is shattered by the arrival of a subpoena requiring Dr Armstrong to testify in criminal proceedings against her patient.

In her statement, Dr Armstrong laments the loss of physician-patient privilege, describing her journey back from the trial at which she gave evidence about her clinic sessions with her patient as 'feeling a sense of betrayal I haven't felt in my professional life'. She notes that many of her colleagues have since confirmed they too have had criminal prosecutions invade their patient relationships.²⁰

Conclusion

There is an element of randomness to criminal HIV prosecutions. With more than 1,000 cases of HIV transmission a year in Australia and a significantly higher number of risk events, usually only one or two cases proceed to trial. Some generalisations can be made. There have been no cases where a condom has been used or where there is consensus that both parties knew the person with HIV had HIV. Beyond that, generalisations are difficult, including cases where HIV was not transmitted. Prosecutions appear to rely more on the willingness of a person to make a complaint and for police to investigate than very specific circumstances regarding sexual acts.

In such an uncertain environment, just what advice should doctors and nurses give? They are not lawyers, and really, the advice that would absolutely protect against a person being prosecuted goes against our understanding of the reality of many people's sexual behaviours; particularly that not all people will use condoms and disclose their HIV status before every sexual activity throughout their lives. Moreover, perceived policing of behaviours will likely undermine patient's willingness to talk honestly with their doctor.

The National HIV Strategy asserts 'support must ... be provided to health care professionals, such as clinicians at the front line of HIV diagnosis and treatment, to ensure they are well informed about legal issues, including their own legal obligations, and can provide optimal information and support to patients'.

At face value that appears constructive however it will only be so if clinical staff are provided the requisite supports to prevent a drift towards a moralising, inaccurate or unnecessarily conservative version of 'the law'.²¹

This is an area in which advocates and researchers need to work with their clinical colleagues to ensure that all that knowledge, amassed over 30 years of clinical practice but often siloed in the health sector (and sitting with individual practitioners), can inform clinical practice and broader criminalisation debates and HIV prevention strategies.

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There is an element of randomness to criminal HIV prosecutions. With more than 1,000 cases of HIV transmission a year in Australia and a significantly higher number of risk events, usually only one or two cases proceed to trial. Some generalisations can be made. There have been no cases where a condom has been used or where there is consensus that both parties knew the person with HIV had HIV.



Zaburoni v The Queen: problems with the legal tests used to determine intention in criminal charges for transmission of HIV

By Alexandra Stratigos

Human rights advocates generally agree that the use of criminal laws to prosecute people for HIV non-disclosure, exposure or transmission should only occur in very limited circumstances and that the favoured approach to addressing behaviours of people placing others at risk of HIV is a public health approach. In 1991 Justice Michael Kirby of the High Court of Australia, as he was then, stated:

‘There will be calls for “law and order” and a “war on AIDS”. Beware of those who cry out for simple solutions, for [in] combating HIV/AIDS there are none. In particular, do not put faith in the enlargement of the criminal law.’¹

As anticipated by the Honourable Michael Kirby, the ‘war on AIDS’ began and criminal laws were applied to offences for HIV non-disclosure, exposure and

transmission; a situation which occurred despite clear evidence that better public health outcomes can be achieved by state health services, who are equipped to appropriately manage – and to detain where necessary – people who place others at risk of HIV.

The use of criminal laws to punish people with HIV who are placing others at risk have negative consequences not just for the individual themselves but also for the broader community. The UNAIDS publication, *Judging the epidemic – A judicial handbook on HIV, human rights and the law* states:

‘There is no evidence that criminal prosecutions [of HIV] help prevent new HIV infections. Rather, there are indications that overly broad criminalisation of HIV

non-disclosure, exposure or transmission undermines public health and can result in miscarriages of justice.’²

So if we are to only use criminal laws for HIV non-disclosure, exposure or transmission in limited circumstances, what circumstances are they?

UNAIDS guidance establishing intent

UNAIDS states that ‘any application of criminal law to HIV non-disclosure, exposure or transmission should require proof, to the applicable criminal law standard, of intent to transmit HIV.’³ The difficulty with this proposition is that ‘the applicable criminal law standard’ varies significantly by jurisdiction, and mental culpability for HIV transmission to a sexual partner is difficult to ascertain.

Intent in a criminal law setting is not to be confused with motive. The relevant criminal law test for intention is whether the person meant to cause the charged result, directed his mind to that result or had that result as his purpose or design.⁴ Awareness that a result is a probable consequence of their conduct alone is not sufficient to prove intent.⁵ Awareness that the result is a certain or near certain consequence of their conduct itself is not sufficient to prove intent at law.⁶

Landmark High Court decision

Australian courts throughout the country have been prosecuting people for both intentional and reckless transmission of HIV since the '90s. This year, the High Court heard the matter of *Zaburoni v The Queen* [2016] HCA 12. This was the first time that the High Court has had the opportunity to examine a criminal HIV transmission case, and consider the issues of when a person may have the requisite intention to transmit HIV to their sexual partner.

Mr Zaburoni contended that he did not intentionally transmit HIV to his sexual partner. On 6 April 2016 the High Court of Australia agreed with Mr Zaburoni and clarified existing law around the issue of intent in a criminal law setting by finding that:

1. *'foresight of risk of harm is distinct in law from the intention to produce that harm.'*⁷

2. *'Where proof of the intention to produce a particular result is made an element of liability for an offence under the Code, the prosecution is required to establish that the accused meant to produce that result by his or her conduct ... knowledge or foresight of result, whether possible, probable or certain, is not a substitute in law for proof of a specific intent under the Code.'*⁸

The High Court's findings draw Australia closer towards what UNAIDS views as best practice, in noting that there can be many reasons why a person may not disclose their HIV status to a sexual partner.

The UNAIDS Guidance Notes 2013, *Ending overly broad criminalization of HIV non-disclosure, exposure and transmission: Critical scientific, medical and legal considerations*, states that:

34. *'Intent to transmit HIV should not be presumed when a person who knows he or she is HIV-positive engages in unprotected sex or has sex without disclosing his or her HIV status. There are many reasons why people may not disclose their HIV-positive status and/or may engage in unprotected sex, including fear of abandonment, discrimination or violence; shame or embarrassment; and/or the psychological inability to accept one's HIV-positive status, often referred to as a person "being in denial" about their status. None of these reasons indicate an "intent to transmit HIV" or a desire to harm their sexual partner on the part of the HIV-positive individual.'*

35. *'Similarly, people may also lie about their positive HIV status for the reasons highlighted above. Thus, active deception—including lying when asked about one's HIV status—may not indicate, on its own, intent to transmit HIV or to cause harm. Prosecutors and courts should not automatically equate deception with intent to transmit HIV or any other culpable mental state. Rather, care should be exercised to determine the nature, context and material circumstances of any alleged deception.'*⁹

The UNAIDS publication, *Judging the epidemic – A judicial handbook on HIV, human rights and the law*, states that:

'A medical diagnosis of HIV-positive status, accompanied by post-test counselling regarding HIV transmission, is usually necessary to establish mental culpability for HIV exposure or transmission. It should be

*noted, however, that even if a person living with HIV has been advised on the risk of HIV transmission, challenges such as language barriers, shock about the diagnosis or other issues may prevent them from completely understanding the transmission risks associated with different activities. A single counselling session or reference document might not be sufficient to inform a person living with HIV adequately about transmission risks.'*¹⁰

These propositions support the assertion that there needs to be something more than denial or lies regarding HIV-positive status to a sexual partner to bring about a charge of intentional transmission. Rather, an accused must have foreseen 'that his or her actions would have an inevitable or certain consequence.'¹¹ In the case of *R v Reid*, the court relied upon the evidence that the defendant had publically taunted the complainant with the fact that he had contracted HIV as a result of sexual contact with the defendant and that he had an appreciation for the risks of transmissions by his comment that he felt like he was 'carrying a loaded gun'.¹²

From a public health perspective, *Zaburoni v The Queen* means that people with HIV who are genuinely intending to transmit HIV to a sexual partner may be prosecuted. At the same time, the decision also protects from criminal prosecution those people with HIV who have not disclosed their status for the varied and complex reasons as articulated by UNAIDS. In those instances it would be difficult to prove beyond reasonable doubt that the person with HIV had a genuine appreciation or foresight as to any certainty or inevitability of the transmission of HIV.

From a public health perspective ... the decision also protects from criminal prosecution those people with HIV who have not disclosed their status for the varied and complex reasons as articulated by UNAIDS. In those instances it would be difficult to prove beyond reasonable doubt that the person with HIV had a genuine appreciation or foresight as to any certainty or inevitability of the transmission of HIV.

Need for prosecutorial guidelines

Zaburoni v The Queen creates some guidance and clarity around the varied reasons why a person with HIV may not disclose to a sexual partner and why this lack of disclosure does not necessarily lead to a conclusion that a person intended to transmit the virus. However, the ability to articulate these propositions to a judge or jury in first instances are sometimes difficult in the context of criminal law proceedings and it may therefore be necessary to ensure that these issues are apparent prior to the commencement of charges being brought. The Honourable Michael Kirby comments that:

*'Prosecutors have their own discretions to ensure the principled deployment of the criminal law. But once a case is brought, a court can only apply the law as it is enacted. It cannot stay the proceedings or postpone them simply because it might believe that criminal prosecutions are ineffective or even counter-productive as a public health strategy to promote behaviour modification.'*¹³

On 3 June 2016 when sentencing Mr Zaburoni, Her Honour Judge Dick JDC also identified the challenges with sentencing people who are charged with offences of either recklessly or intentionally transmitting HIV to a sexual partner.

Judge Dick JDC made reference to the report by Mr Zaburoni's treating HIV specialist that highlighted the barriers to people disclosing their HIV status including cultural factors and difficulties adjusting to an HIV diagnosis.

Historically in Australia, charges for HIV transmission have been brought where the complainant and the defendant have engaged in sexual intercourse on multiple occasions; as highlighted by Judge Dick JDC, this offence therefore differs from other charges of grievous bodily harm that involve a single act or event resulting in the harm. It is therefore also usually impossible to pinpoint the exact event which resulted in the complainant becoming HIV-positive.

It is for these varied and complex reasons that it is essential that HIV advocates progress the need for prosecutorial guidelines. Police, lawyers and the judiciary need to be able to recognise that issues around HIV transmission and intent are unique and a standard criminal law approach may not be the best approach. Lawyers also need to be well versed in the issues surrounding HIV non-disclosure, exposure and transmission and on how to adequately represent their client in HIV non-disclosure charges, and refuting, when necessary, the assumption that non-disclosure or lying about one's status equates to intentional transmission of HIV.

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Understanding the lives of young gay men: community-based research and evaluation

By **Sally Cameron**

July marked the end of AFAO's four-year project to better understand the lives of young gay and same-sex attracted men, with the primary aim of enabling AFAO and its members to better target HIV health promotion materials to these men. Although such work has been ongoing since the beginning of the HIV epidemic, this particular story arc started amidst heated discussion about whether HIV infections were or were not increasing among this group, driven by epidemiological data from 2012 that suggested a rise in HIV diagnoses among gay men under 25 years old.

To better understand what these data may mean, and where and how HIV risk might fit amidst the multiplicities of young gay men's lives, AFAO undertook a research process that cut across the often siloed spaces of academia, community-based service provision and, of course, the lives of young gay and same-sex attracted men themselves.

Reviewing available research

AFAO's Young Gay Men project began with a review of (mostly Australian) research, which was consolidated in a

discussion paper entitled, *Are young gay men really so different? Considering the HIV health promotion needs of young gay men* (April 2014).¹

Concurrent to the release of this paper, AFAO convened a seminar on Young Gay Men and HIV risk, held as part of the 2014 Social Research Conference on HIV, Viral Hepatitis and Related Diseases. At this seminar, leading academics Philippe Adam, Kath Albury, Ben Bavinton, Duane Duncan and Martin Holt presented their research – most of which was so recent it had not yet been published. This work suggested that earlier data was most likely a glitch and young gay men were probably not at increased or increasing risk. It also suggested that while young gay men may not actually be at increased risk, there may be particular factors influencing their risk-taking behaviours.

Young gay and same-sex attracted men are living very different lives from their counterparts a generation ago. Without an AIDS crisis, HIV has lost currency, and for many, HIV seems a somewhat outdated and peripheral concept. Similarly, use of the term 'gay' as an identifier is not necessarily a comfortable or consistent

fit for many of these men. Given less of a reliance on 'gay community', a loss of gay social spaces and the rise of the internet, standard sites of HIV health promotion are shifting and young gay men are not 'seeing' traditional HIV health promotion messaging.

Accordingly, the research suggested the importance of further exploring particular sites of HIV intervention, and made reference to the poor performance of school-based sex and sexuality education; the increasing importance of identities such as queer; the need for mental health support and youth spaces; the significance of internet and 'dating' apps; and the resource intensive nature and complexity of using diverse ICT (information and communications technology) platforms.

Consolidating community sector feedback

Next, AFAO undertook a scoping study of 24 HIV, youth and mental health agencies to develop a stronger, current, localised account of same-sex attracted young men's HIV risk. That exercise confirmed the importance of peer education, targeted campaign materials, youth specific events,



Tag cloud of responses to the statement: 'The Young Gay Men I Know Feel ...'

web-based resources, social media and online networks. The project generated the production of *Guiding Principles of Young Gay Men's HIV Health Promotion*², which also identified some major health promotion challenges, including that:

- core health promotion settings are shifting
- targeting is more complicated
- strategic messaging and format varies by region
- organisations require increased capacity (including technical skills)
- lesbian, gay, bisexual, transgender and intersex (LGBTI) sex education in schools remains inadequate.

A recurring theme was the need for youth participation and ownership.

Grass roots input

Finally, the project turned to the direct investigation of experiences and knowledge of young gay men. AIDS Councils from around Australia selected 22 young gay men to complete a series of 'cultural probes' tasks. Participants were asked open-ended questions about their health priorities. Their answers revealed a range of approaches indicating a broad approach to health and wellness.

Participants were also asked to describe the attitudes of other young gay men they know about sexual health. Their answers reflected a mix of feelings ranging from negative (e.g. insecure, paranoid) to positive (empowered, indestructible), making it quite clear that simplistic representations will fail to engage and influence this target group.

As a means to find out what kind of information and advice young gay men would give to other, perhaps younger

gay men, participants were asked, 'What would you say to a young gay man starting to have sex?'. Their responses included the following six key themes:

1. Don't rush into sex or particular sexual practices
2. Don't feel pressured
3. Practice safe sex
4. Enjoy sex
5. Make sure you're well informed (about types of sex and safe sex practice)
6. Don't let things get out of control.

Perhaps unexpected was the degree of caution young men included in their advice. Their input served as a timely reminder of the importance of recognising the developmental nature of sexuality, sexual experience and sexual confidence, including understandings of romance and willingness/capacity to negotiate in both sex and relationships. Health promotion aims to enable people to increase control over their health. It is important that 'sex positive' messaging does not ignore the developmental and diverse nature of sexuality and is supportive of people making whatever decisions about sex are in their own best interest.

Practice

The young gay men's project is not just a classic example of research to ensure health promotion practice is evidence based, it also demonstrates how the health promotion development process can generate findings of its own. Grassroots agencies don't just draw on research; they also discover and articulate current trends. Moreover, because there's no waiting for a protracted peer-review publication process, and given the immediacy of their location, community agencies doing this work are well placed to identify what is happening out there (right here), right now.

Output

The Young Gay Men's Project research has gone on to inform the development and production of a campaign for young gay men, call OUTspoken (www.outspoken.org.au). The key resources for this campaign are a series of videos of young gay men sharing their stories. This is to help ensure strong youth participation in the campaign (a recurring theme from the *Guiding Principles of Young Gay Men's HIV Health Promotion*).

These young men share their stories on topics such as coming out, meeting people and relationships, sexual health, HIV prevention, stigma and sexually transmissible infections (STIs). The videos are housed on the dedicated campaign website, but importantly, there are also videos designed specifically for sharing on social media channels to promote engagement with the stories of these young gay men and the campaign. The campaign is also supported by a range of posters, and online and social media advertising to introduce the young men and their stories.

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Queer Wars

By Dennis Altman and Jonathan Symons. Polity Press, Cambridge, 2016.

Reviewed by **Abigail Groves**

Some time in 2013, I had dinner with a group of MPs from Uganda. To my racist surprise, they were all very well-educated and spoke perfect English. They were also very earnest and took their role as members of parliament very seriously. One young man explained how he was trying to establish a salt processing plant in his local community, which had lots of natural salt. Having bonded sufficiently, I asked him about Uganda's anti-homosexual legislation, which was then before the parliament.

'This behaviour,' he said emphatically, 'is not Ugandan.'

Not *Ugandan*, I thought? What on earth has sexual preference got to do with being Ugandan?

It is this intersection between national – and international – politics and gay rights that Dennis Altman and Jonathan Symons explore in their short book *Queer Wars*. Why is it, they ask, that as homosexuality has become more visible globally, in many parts of the world, reactions to sexual and gender diversity have become increasingly polarised? (p 3). At the same time as western countries are moving to legalise same-sex marriage, why is it that others in Eastern Europe, Africa and the Middle East are moving in the opposite direction, stepping up persecution of gays and introducing repressive legislation?

The answer, according to Altman and Symonds, is that in non-western countries, acceptance of gay and trans identities is increasingly associated with modernisation and westernisation. And not everybody wants to be modern and, particularly, western. This hypothesis makes some sense even in the west, and may have played a role in incidents such as the North Carolina bathroom legislation or even the Orlando massacre. Altman and Symonds, however, are concerned with those countries that have a history of colonial exploitation.

'In many parts of the world,' they argue, 'repression of homosexuals may be acquiring a ... symbolism as an expression of national identity and defiance' (p 26). Hence in Uganda, opposition to gay rights has become synonymous with rejecting colonialism and asserting an authentic Ugandan patriotism. Even in Russia, which was never subject to colonialism but which lost its superpower status after the fall of communism, repression of gays is increasingly seen as an assertion of traditional Russian values and Russian independence.

No doubt African men have always had sex with other men. Likewise, Russia has an honourable homosexual history – just look to Tchaikovsky. But the point here is different. The emergence of 'gay', 'lesbian' and 'transgender' as specific, *public*, identities is a new and peculiarly western phenomenon. The gay characters in American TV shows, for example, might seem innocuous and de-sexualised to us. For Russian gay men and lesbians, they might appear as a longed-for affirmation of their own aspirations. But for many heterosexual Russians they are offensive, threatening and *foreign*.

Moreover, Altman and Symonds attribute the growth of this backlash in part to western gay activism. The well-meaning interventions of western gay activists are often ignorant of local realities and, more disturbingly, can even be counter-productive. Altman and Symonds caution against 'well-meaning egoism' in international activism. To my mind, this is the most interesting part of their analysis – it is a shame that they don't develop it further.

Indeed, *Queer Wars* is frustratingly short. With such a broad scope, Altman and Symonds have little time for detailed analysis of the particular manifestations of homophobia that have emerged in different parts of the world. It's easy



enough to understand, for example, how the phenomenon of 'corrective rape' of lesbians may be connected to both sexism and homophobia. But why has it emerged in South Africa, rather than in, say, Russia? It would be good to see questions like this explored.

Altman and Symonds also skip over many of the sensitivities of queer discourse, using the term 'queer' when they really mean 'gay men'. Beginning a chapter on the 'conservative backlash,' for example, they say, 'Crucial to queer movements since the 1970s is the assertion of homosexuality as an identity' (p 93). Ahem, in the 1970s 'queer' was still an insult. And no, 'homosexual' does not include lesbians. A fuller treatment of the issues would have allowed them to deal with these minor irritants. But such quibbles aside, the book is a valuable read and without doubt, 'queer wars' is a more appropriate title than 'gay wars'.

Dr Abigail Groves is a freelance writer and a former Policy Analyst at AFAO.

ZERO: NO LINKED HIV TRANSMISSIONS IN PARTNER STUDY AFTER COUPLES HAD SEX 58,000 TIMES WITHOUT CONDOMS

By Simon Collins

The PARTNER study provides good evidence that undetectable viral load might be a threshold below which sexual HIV transmission does not occur. The importance of the PARTNER study is that it included both gay and straight couples, that it measured risk in people who were not using condoms and that it estimated absolute risks.

Previous studies have been almost exclusively in heterosexual people who still reported high rates of condom use. The PARTNER study provides more than three times the amount of follow-up time from people not using condoms than all the previous studies combined. This includes 500 couple-years of follow-up from people having anal sex without condoms.

Between September 2010 and May 2014 the PARTNER study prospectively enrolled 1,166 serodifferent couples at 75 clinical sites in 14 European countries. Entry criteria included that the HIV-positive partner had an undetectable viral load on commencement of antiretroviral therapy (ART) and that the couple were not always using condoms when they had sex.

Follow-up included routine sexual health checks (including HIV testing for the HIV-negative partners) and each participant also completed sexual history questionnaires to look at risk for different activities. Couples were only included in the final analysis when the most recent viral load for the positive partners was undetectable – defined as <200 copies/mL. The primary endpoint was the rate of within-partner transmissions, determined by phylogenetic analyses for all couples in which the negative partner became positive.

Results

Of 1,166 couples enrolled, 1,004 couples had at least one follow-up visit and 888 couples provided 1,238 couple years of follow-up. This included 548 heterosexual couples and 340 gay male couples.

None of the 11 incident HIV infections in negative partners (ten gay and one heterosexual) were phylogenetically linked to the HIV-positive partner. Most people (8/11) reported having sex without condoms with people outside the main relationship.

The ongoing PARTNER 2 study continues to follow up gay couples in the PARTNER study and to recruit additional gay couples, in order to produce a similarly powered evidence base for gay men as for straight couples, with follow-up until 2019.¹

Also of note during the study, 91 HIV-positive partners reported other sexually transmissible infections (STIs) (n=16 heterosexual men, 16 heterosexual women and 59 gay men) – closely matching STIs in the negative partners, also without any increased risk reported for HIV transmission.

Comment

These results are simple to understand – zero transmissions from over 58,000 individual times that people had sex without condoms. They are also notable for the complexity of the analysis that was needed to prove that none of the new diagnoses were linked transmissions from within the couple.

Together, this provides the strongest estimate of actual risk of HIV transmission when an HIV-positive person has undetectable viral load – and that this risk is effectively zero. While no study cannot exclude the possibility that the true risk might lie within the upper limit of the 95%CI, even if the true value is actually zero due to some as yet unproven mechanism, the 95%CI can never be zero, just becomes increasingly close. Neither the presence of STIs nor likely viral load blips between tests had any impact in enabling transmission.

The results provide a dataset to question whether transmission with an undetectable viral load is actually possible. They should help normalise HIV and challenge stigma and discrimination.

The results challenge criminalisation laws that in many countries, including the United States, continue to imprison hundreds of people based on assumptions

of risk that these results disprove, even when condoms are used and viral load is undetectable.

Activist Sean Strub, from the SERO project (www.seropproject.com) said: 'Hundreds of people living with HIV in the US have been charged with criminal offences for the perceived or potential risk of HIV exposure or transmission. Some are serving or have served long prison sentences for spitting, scratching or biting and others for not being able to prove they had disclosed their HIV-positive status before having sexual contact (even in the absence of any risk of HIV transmission). HIV criminalisation has created a viral underclass in the law, further burdening a disenfranchised community, putting a disproportionate share of the shared responsibility for preventing sexually-transmitted infections on one party, and discouraging people at risk from getting tested for HIV.'

The results will also positively impact on the quality of life for both HIV-positive and HIV-negative individuals who are in serodifferent relationships, irrespective of the choice to use condoms.

**Adapted from: i-Base.info
HIV Treatment Bulletin
(July/August 2016)
Published: 12 July 2016.**

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Simon Collins is a community representative on the steering committee of the PARTNER study.

LESS FREQUENT CD4 AND VIRAL LOAD MONITORING SAFE FOR PEOPLE DOING WELL ON ART

By Michael Carter

The frequency of routine monitoring for people treated with antiretrovirals with viral suppression can be safely reduced from every three months, to every six months, investigators from Europe

and the United States report in the 1 June edition of the *Journal of Acquired Immune Deficiency Syndromes*.¹ However, people followed-up every nine to twelve months were more likely to experience virologic failure and also had lower CD4 count increases compared to people monitored every three months.

‘We found little evidence of an effect of monitoring frequency on death or AIDS-defining illness or death in the short term among individuals who achieve virologic suppression within 12 months of cART (combination antiretroviral therapy) initiation’, comment the authors. ‘Our findings suggest that monitoring every 9–12 months increases the risk of virologic failure ... this might reflect intermittent adherence among individuals monitored less frequently.’

The benefits of immunologic and virologic monitoring for people with HIV is well known. However, there are few data to inform the frequency of follow-up for people doing well on HIV therapy.

Current European guidelines recommend frequent CD4 and viral load monitoring following the initiation of antiretrovirals, with check-ups every three to six months once viral load is suppressed to below 50 copies/ml and CD4 count has increased to over 500 cells/mm³. In contrast, US guidelines recommend viral load monitoring every one to two months after treatment initiation, with frequency reduced to every three to four months once viral load is undetectable; and after two years of viral suppression, the frequency of monitoring is further reduced to every six months.

These guidelines also recommend CD4 count monitoring every three to six months in the period after starting treatment, with a decrease in frequency

to every 12 months for people with an undetectable viral load and CD4 count above 300 cells/mm³ for two years. ASHM (the Australasian Society for HIV, Viral Hepatitis and Sexual Health) provides an Australian commentary based on the US Guidelines for use by Australian clinicians.²

Given this uncertainty, investigators from the HIV-CAUSAL (HIV Cohorts Analyzed Using Structural Approaches to Longitudinal data) Collaboration³ used data from six large observational cohort studies in Europe and the US to assess differences between three CD4 and viral load monitoring strategies. Data were available for approximately 39,000 adults who started HIV therapy after 2000 and who achieved viral suppression within 12 months of treatment initiation.

People were monitored according to one of three strategies: every three months; every six months; and every nine to twelve months.

Two main outcomes were compared between these three strategies:

1. Clinical all-cause mortality and a combined end-point of AIDS or death within 24 months of follow-up.
2. Virologic failure (sustained increase in viral load above 200 copies/ml) and CD4 cell increase within 18 months of follow-up.

During follow-up, there were 265 deaths and 690 AIDS-defining illness or deaths.

As regards virologic failure, people monitored every six months were somewhat less likely to experience a sustained rebound in viral load to above 200 copies/ml compared to those with three-monthly follow-up. However, people monitored every nine to twelve months were significantly more likely than those monitored every three months

to experience virologic failure. Using a viral load threshold of 50 copies/ml altered the results somewhat, but people with nine-to-twelve month monitoring were still more likely to have virologic failure compared to those with the most frequent follow-up, though the difference was no longer significant.

The mean baseline CD4 count was 397 cells/mm³. After 18 months of treatment, this had increased to 506 cells/mm³ for people who had check-ups every three months, compared to 501 for people followed-up every six months and 475 cells/mm³ for those monitored every nine to twelve months.

‘The mean CD4 count at 18 months was greater than 400 cells/mm³ for all of the monitoring strategies, and so the clinical relevance of these differences could be debated,’ suggest the investigators.

‘Our findings suggest that less frequent monitoring of individuals on cART with confirmed virologic suppression has little effect on clinical outcomes by 18 months of follow-up,’ conclude the investigators. ‘Because effects of different monitoring strategies could take years to materialise, longer follow-up is needed to fully evaluate this question.’

Adapted from aidsmap.com

Published: 13 June 2016

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