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Mobilisation, politics, investment and constant adaptation: lessons from the Australian health-promotion response to HIV

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Abstract

Issue addressed: The Australian response to HIV oversaw one of the most rapid and sustained changes in community behaviour in Australia's health-promotion history. The combined action of communities of gay men, sex workers, people who inject drugs, people living with HIV and clinicians working in partnership with government, public health and research has been recognised for many years as highly successful in minimising the HIV epidemic.

Methods: This article will show how the Australian HIV partnership response moved from a crisis response to a constant and continuously adapting response, with challenges in sustaining the partnership. Drawing on key themes, lessons for broader health promotion are identified.

Results: The Australian HIV response has shown that a partnership that is engaged, politically active, adaptive and resourced to work across multiple social, structural, behavioural and health-service levels can reduce the transmission and impact of HIV.

Conclusions: The experience of the response to HIV, including its successes and failures, has lessons applicable across health promotion. This includes the need to harness community mobilisation and action; sustain participation, investment and leadership across the partnership; commit to social, political and structural approaches; and build and use evidence from multiple sources to continuously adapt and evolve.

So what? The Australian HIV response was one of the first health issues to have the Ottawa Charter embedded from the beginning, and has many lessons to offer broader health promotion and common challenges. As a profession and a movement, health promotion needs to engage with the interactions and synergies across the promotion of health, learn from our evidence, and resist the siloing of our responses.

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Introduction

The Australian response to HIV oversaw one of the most rapid and sustained changes in community behaviour in Australia's health-promotion history, and has been referred to as a 'public health milestone of global importance'[1]. By international standards, Australia has been able to sustain this behaviour change and to achieve relatively low prevalence over the 30 years of the epidemic (Fig. 1).

However Australia has experienced both successes and failures throughout the response. Australia experienced a rapid decline in HIV diagnoses from the mid-80s through to the end of the 90s. It then experienced a brief plateau followed by a slow but steady increase in HIV diagnosis from around 2000 through to 2006, and there were indications of another possible plateau from 2007 to 2011 (Fig. 2). In 2012, Australia again experienced indications of increased infections in gay communities and new emerging epidemics in

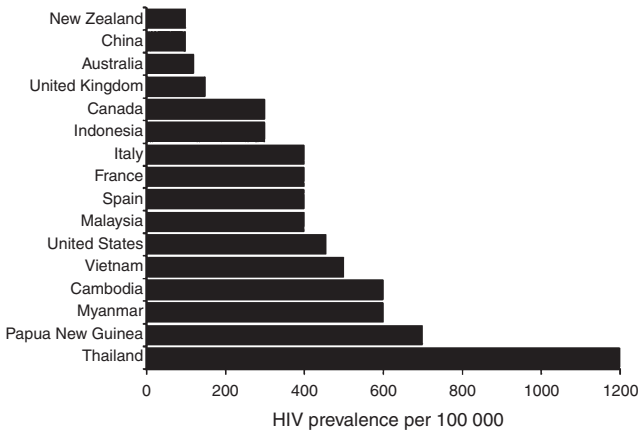

Fig. 1. HIV prevalence in selected countries (2013).[23]

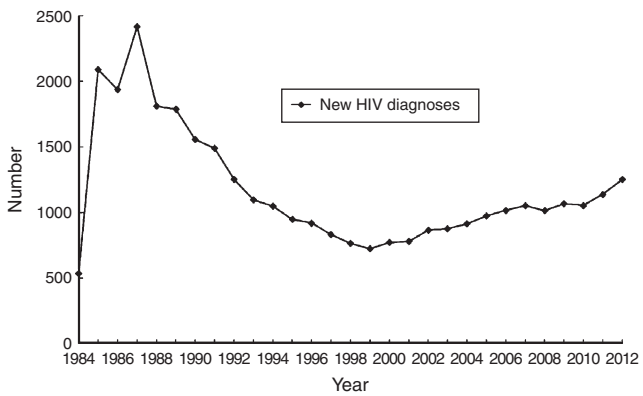

Fig. 2. Newly diagnosed HIV infection in Australia.[23]

other communities, such as people travelling to and from countries with high HIV prevalence; however, these have continued to be lower than most comparable countries.

This article will describe how communities of gay men, sex workers, people who inject drugs, people living with HIV (PLHIV) and clinicians, government, public health and research mobilised to respond to the HIV crisis, and how the response evolved from a crisis response to an ongoing adaptive response. To illustrate this, the past 30 years are divided into key periods in the epidemic. Drawing on examples of the successes, challenges and failures, the article identifies key lessons for broader health-promotion policy, programs and workforce development. The story is broad and complex and, in the interest of brevity, most examples have been limited to one of the populations most affected by HIV, being gay men. There are many other examples, such as the experience of programs working with injecting drug users and sex workers, that have maintained extremely low rates of HIV infection and that demonstrate similar themes and lessons.[1]

1981 to 1995: from crisis to sustained response

Much of the revolutionary nature of what occurred in this early period of the HIV response [1–3], is masked by many of the innovations that are now standard practice in health promotion. In fact, much of the initial decline in HIV diagnosis, led by mobilised communities, preceded the first national strategy and its related campaigns.[1]

Affected communities mobilised to focus on the HIV crisis, building on already existing though limited rights-based movements across gay and lesbian communities, drug users and sex workers. These emerging movements were faced with not only dying friends, lovers and peers, but also significant rises in discrimination, violence and denied services due to the social reaction to HIV. Affected communities were positioned in the media and policy discourse simultaneously as at risk and as risk[4] and working in HIV care or prevention was considered by many as career damaging.

In response to this, terms such as 'people living with HIV/AIDS' rather than AIDS victims, the AIDS Coalition to Unleash Power (ACT-UP), 'nothing about us without us', and 'treatments activism' built on the 60s and 70s social activism and entered the health promotion and health policy lexicon. The term 'safe sex' was developed by gay communities in the USA, responding to calls for gay men to cease having sex. By the mid-1980s, affected communities had established State and National organisations across Australia.

It was in this politically fraught environment that Australia forged a bipartisan approach and affected communities with clinicians, researchers, government, public health advocates and others formed what became to be known as the Australian HIV partnership. It was not an easy partnership, and was in direct contrast to the approach of most other countries at the time.[2,5,6]

This period was also characterised by not waiting until all the evidence was fully developed and refined. It meant trusting in the knowledge and experience within the partnership,[3] and resisting the presentation of ideology and moral dogma as evidence. It was during this period that the Ottawa Charter was being formed and promulgated, allowing the core principles to be embedded in the Australian HIV response from the beginning. The pragmatism, boldness and partnership meant Australia's Government had established national advisory structures and the beginnings of a coordinated national response before President Reagan had even mentioned HIV in any US policy speech.

Many early education activities were funded by affected communities and illegal in many states, such as needle and syringe programs, education about sex for gay men and peer empowerment for sex workers, and community workers and clinicians often risked criminal charges. Regulations had to change to even allow condoms to be sold in grocery stores, let alone decriminalising homosexuality, sex work or drug use. It could be argued that where effective tobacco strategies brought in regulation over time in order to have an effective and sustained strategy, the HIV response had to remove regulation and restrictions for the same purpose.

Much was also learnt during this period about the counterproductive impact of fear-based campaigns that increased discrimination and decreased testing and engagement by those communities most at risk.[3] Both successes and mistakes were made during this period and lessons learnt.

The value of investment in cutting-edge social, cultural, clinical and epidemiological research, embedded within the HIV partnership, was also demonstrated. This supported and sustained strong relationships and rapid translation back and forth between research and practice. One example was research with gay men that identified that widespread HIV testing was enabling cultural practices such as negotiated safety – where much of the unprotected sex within gay men's relationships was potentially safe as it took place within negotiated safe sex agreements that were tailored to different relationship formats and HIV status.[7,8] Another example was that by the mid-1990s it was evident to community educators and researchers that gay men's and gay community's relationships to the HIV epidemic were changing. Dowsett and McInnes[9] coined the term 'post-AIDS' to describe how gay men were starting to construct their lives as gay men without being in response to AIDS. This was not saying the crisis was over – but that the epidemic was being assimilated into a culture. As is the case in many other health or social issues, a community cannot live in crisis mode forever but will adapt. and health promotion needed to recognise and adapt to that.

Health promotion's strength in HIV was to engage with the reality of intimate and cultural practices, not just behaviour. It was about working with evolving safe sex and safe injecting cultures, rather than an individual deficit approach. Engaging with how communities use and respond to knowledge and practices, and leveraging the strengths rather, than working against them, was central.

1996–2006: new hope, disinvestment and political neglect

In 1996, the success of new combination, highly active antiretroviral therapies (HAART) was announced and was a key marker of a change in the relationship between the medical and social aspects of HIV. Shortly afterwards, post-exposure prophylaxis measures for exposure to HIV were presented, as well as findings concerning multi-drug-resistant strains of the HIV virus. HAART changed the face of AIDS.[4] By 1998, there were celebrations that for the first time in over 15 years there was an edition of gay community press without an AIDS-related obituary.[10]

During this period, Australian social and epidemiological research with gay men found that:

- Most gay men were still using condoms most of the time, but there was gradual rise in the number of gay men who reported occasional unprotected anal intercourse with casual partners (UAIC);
- The internet and mobile technology were emerging as facilitative tools in gay men's social and sexual networks, and this had a capacity to both increase and decrease risk of transmission;
- Some gay men were developing risk-reduction strategies without using condoms, including negotiated safety in relationships, decision-making about sexual positions on the basis of HIV status, and negotiating HIV status disclosure in different casual settings; and
- There were early signs of an association between optimism about HIV treatments and UAIC.[11–15]

This was also a time of consolidation of national HIV/AIDS policies that shifted from the innovative, community and crisis-driven time of the early epidemic to a more 'traditional' and 'institutionalised' response that had 'seen a growing resistance to community participation'.[16] There were claims of redirected resources to other health issues, increasing conservatism in relation to strategies and funding to HIV, and the reduced participation of affected communities or service providers within peak ministerial committees for HIV.[17]

From 1999 to 2006, there were small but steady increases in HIV diagnosis in Australia (Fig. 2), with the majority of all diagnoses being from sex between men. Among gay and other men who have sex with men (GMSM), HIV diagnoses increased 39% between 1999 and 2006 (719 to 997). Similar or higher increases were occurring among GMSM in most comparable cities internationally.[18] However, when the increases were analysed by state, there was considerable variance. New South Wales experienced only an 8% increase in notifications among GMSM (249 in 1999 and 270 in 2005), whereas Victoria experienced a 131% increase (78 in 1999 to 180 in 2005) and Queensland a 55% increase (66 in 1999 to 102 in 2005).[19] For the first time in some years, the HIV partnership drew together and undertook an exhaustive examination of the epidemiological, social and behavioural research, policy, testing and treatment, and health-promotion strategies and structures in order to understand the state-based differences, which effectively provided a natural experiment in HIV prevention.[20,21] The result was there were differences in structural factors between the states in the way the HIV partnership functioned, types of prevention strategies supported, the level of financial investment in prevention activities, and proportional size of the prevention workforce.[22] Continuing high-level coordinated leadership and commitment to resourcing of HIV prevention by all stakeholders in the HIV partnership was crucial for a successful and sustained response to HIV. In other words, those states that had reduced investment and capacity were less successful in responding to the complexities of changing epidemics, social practices and cultural engagement. The experience highlighted the vulnerabilities of success in health promotion resulting in reduced resources and momentum.

Fortunately, during this period Australian programs continued to maintain extremely low rates of HIV infection among injecting drug users and even lower among sex workers, despite political and capacity vulnerabilities. Australia also saw the beginnings of increasing diagnoses among people who travel from and to

countries of high HIV prevalence in line with international trends regarding HIV and mobility.[23]

2006 to today – adapting, advocating and the promise of combination prevention

In the past few years there has been a significant increase in the evidence indicating the potential of antiretroviral drugs to play a critical role in preventing transmission of HIV. Most notably, the HIV Prevention Trials Network's HPTN 052 trial, which demonstrated a 96% reduction of HIV transmission among serodiscordant heterosexual couples where the HIV-positive partner was being effectively treated,[24] resulting in a game changing relationship between treatment and prevention. In accordance with this, there has also been an increasing recognition of the need to integrate behavioural and biomedical interventions with broader social, structural and human rights approaches for HIV prevention – coined as 'combination HIV prevention'[25,26] and presented as an analogy to combination HIV treatment. The emphasis of combination prevention is to achieve a strategic and coordinated combination of behavioural, community, biomedical and structural intervention strategies, and not only select the politically palatable interventions from each domain or implement as unrelated parallel interventions.[27]

As readers of this journal would recognise, combination prevention is largely consistent with and influenced by the tenets of the Health Promotion Charter. The implications of these developments for policy and strategy in HIV epidemics are yet to be fully realised and there are significant health service, social, behavioural and system-level changes required if the benefits are to be achieved.[28–30] For example there have been significant policy reforms required to: increase access to convenient and targeted modes of HIV testing (such as rapid HIV testing technology); reduce barriers to PLHIV choosing to go on treatments earlier than previously recommended; and to increase community-level understanding and mobilisation about the broader set of tools for HIV prevention. This will again require all members of the HIV partnership to play their role.

The developments in the role of treatments to support HIV prevention, the global articulation of the relationship with structural and legal conditions,[31] Australia's leading role in the development of the United Nations Declaration on HIV,[32] and the upcoming International AIDS Conference in Melbourne in 2014 (which will be the largest health or development conference ever held in Australia) has seen a convergence of opportunities where the HIV partnership has been able to leverage political energy. The response has already seen major adaptations and re-emerged boldness in programs targeting gay men and PLHIV in some jurisdictions.[33]

However, there is still much to do in HIV in regard to structural barriers and enablers. Criminal sanctions relating to HIV transmission, the lack of drug law reform and the continued criminalisation of sex work has continued to hamper evidence-based health promotion as articulated by the papers from the legal working group of the Commonwealth Ministerial Advisory Committee on blood-borne viruses and sexually transmissible infections.[34] In many areas, ideology has been placed above evidence in policy reform and placing sex workers, drug users and PLHIV at increased risk of physical and social harm with no evidence of benefit to broader community health. Additionally, the potential public health benefits of increased voluntary testing and treatment have dramatically increased the need and urgency for unhindered access to these technologies. To date, Australian governments have demonstrated little ability to overcome the regulatory blocks that have left Australia trailing other developed countries in its access to these technologies. Structural impediments such as this limit and undermine the impact of social and behavioural health-promotion strategies.

This highlights the integral role of advocacy supported by epidemiological, social, and behavioural research and strong program and system-level evaluation, and the capacity to take bold steps.

Discussion

Drawing on the experience of the Australian HIV response, the following lessons were identified as most applicable to the broader health-promotion sector.

Harnessing community mobilisation and action as a central role in health-promotion outcomes

The community HIV responses drew on the emerging conceptual frames of health promotion and community development, but in an environment of large-scale, community-led crisis response. It wasn't primarily a professional response led from inside agencies and institutions; it was a mobilisation response and discourse lead in bars, lounge rooms and backrooms. Community mobilisation in HIV was not only about changes in behaviour – it was also about changing laws and policies, health and social services, ensuring participation in quality research, ensuring a human-rights-based response, and challenging prejudice, ideology and dogma as barriers to effective health promotion.

Community mobilisation and action is, by nature, often outside the control of health-promotion strategies. It is difficult to manage, non-linear and can seem messy. However, it is a major resource central to health promotion because it's the behaviour and social practices of people and communities that we're hoping to influence (both as individuals, as well as their support for social and structural change).

Sustaining participation, investment and leadership across the partnership

The Australian partnership approach to HIV has been fairly durable, though not without periods of disharmony or different levels of participation and/or commitment. Pressure from within as well as from outside has been exerted on partners integral to establishing the community momentum, political and financial resources, bold

pragmatism, and human-rights foundations of the broader response. Consistent with the Ottawa Charter, the Australian HIV response has shown that sustained interventions working across multiple social, political, economic, behavioural and health-service levels, operating within enabling social and legal environments, are the most likely to reduce the transmission and impact of HIV.

A partnership across community organisations, health services, public health, law enforcement, political parties and activists, researchers and clinicians is not easy to maintain. The pressure for consensus across a partnership can alienate diverse views or partners with competing or changing priorities. The roles and contributions across such a partnership are different but all important to achieve and sustain changes across behaviour, culture and policy. Australia's response to HIV also demonstrates that partnerships are not static. In the same way as a community cannot live in crisis mode forever – nor can a partnership response. Partnerships in times of crisis, which necessitate collaboration, are more easily characterised as successful. However, partnerships in times of stability, or when the response needs to become more complex, are much harder work to sustain. The 'natural experiment' of 2000 to 2006 with different levels of HIV health-promotion investment and leadership across States illustrated the impact of these circumstances – reduced resources undermined the capacity to predict, adapt and respond to a continuously changing environment. This period provides compelling evidence to the whole health-promotion sector that leadership, advocacy and investment do matter and do work and, importantly, illustrates what happens when these are allowed to falter.

Committing to social, political and structural approaches

While different terms may have been used over time, the Australian HIV response has always worked with a socio-cultural, structural and systems perspective. HIV health promotion in Australia has, for the most part, resisted taking an individualist perspective in its approach with affected communities. Such an approach tends to see communities as risk takers caused by deficits such as irrationality, youth, low self-esteem, depression or isolation, and the focus is on the individual in the community who needs to be counselled or taught skills. However, where health promotion takes a socio-cultural interactive perspective, the focus is on the cultural and interactive practices and structures that produce opportunities where HIV transmission may occur.[4] It recognises that health promotion in sexual health or harm reduction is not a restrictive, prohibitive or directive approach but a collaboratively produced resource and catalyst[35] that is taken up and used within a complex mix of factors such as relationships and emotions, HIV status, relative risks, social interactions, settings, contexts and legalities. It is in this complexity that programs based within the community and culture, such as peer education and influence, community empowerment and engagement and peer-led social marketing, have such advantage. HIV has been a pioneer in the validation of many peer-based approaches, with injecting drug users, sex workers, PLHIV and gay men. Health promotion that takes this perspective focuses on the collective understandings that produce and sustain particular social and cultural practices. It is the community as interactive process that is addressed, not just the individual.

However, these programs do not operate in isolation. The Australian HIV response is an example to health promotion that broader structures, systems and legal and policy frameworks may have more to do with the success or failure of a program than just the internal program efficacy and quality. It also provides an example of a partnership working together to circumvent these barriers and build the enablers.

Building and using evidence from multiple sources to continuously adapt and evolve

The HIV response has had to adapt and evolve to continuous social, cultural, legal, technological, epidemiological and even generational change. Many complex public health challenges have been termed 'wicked' problems'[36] referring to policy issues that are continually evolving, have many causal levels and usually require innovative and comprehensive solutions involving communities and stakeholders in policy-making and implementation, and which need to be modified in light of experience and on-the-ground feedback.[37] It highlights the need for real-time monitoring, evaluation and learning to feed into decisions. HIV has these hallmarks, but Australia's response to it also demonstrates the potential for inroads to be made where intensive, coordinated and sustained effort is applied.

For example, the continuous evolution of the safe sex culture within gay communities has incorporated risk-reduction strategies through the use of condoms, expanding sexual repertoires to accommodate non-penetrative practices, HIV test results, negotiated safety, strategic positioning and, more recently, viral load and pre-exposure prophylaxis. Not all enjoyed equal popularity but each grew from approaching health-promotion strategies innovatively. As with all health promotion, wicked problems require investment in continuous evidence building from both practice and research to support policy and program refinement and reorientation. This allowed research and practice to challenge the simplistic explanation of changes to behaviour as 'complacency', providing evidence of affected communities' broad, informed and changing decision-making and the place of pleasure and emotion, which is taken as given for others in the community.

Health promotion needs a well developed workforce that understands complexity and nuance, and how to translate that into effective community engaged programs. This workforce needs to draw on and synthesise evidence from multiple sources, as well as have the capacity and policy environment to take bold steps when evidence is limited, and resist simplistic answers, ideology or discrimination being substituted for evidence. Building evidence is critical, but it will not speak for itself or automatically translate into policy and practice without a mobilised and articulate health-promotion workforce and mobilised communities demanding solutions.

Conclusion

Sustaining a continuously adapting and effective response to HIV has required: leadership and participation from affected communities; national and state-level policy reform and infrastructure; reorientation of health services; research investment; adaptations to new treatment and prevention science; challenging personal, social and structural level stigma, prejudice and discrimination; and boldness in the face of sensitivities and legalities around sex, sexuality and drug use.

The Australian HIV response was one of the first health issues to have the Ottawa Charter embedded from the beginning, and has shown that an adaptive and politically active response working across multiple social, political, economic, behavioural and health-service levels, operating within supportive environments, are the most likely to reduce the transmission and impact of HIV. To achieve this requires sustained investment and leadership.

The experience of the response to HIV has lessons that are applicable across health promotion including: the need to harness community mobilisation and action; sustain participation and leadership across the partnership; commit to social, political and structural approaches; and build and use evidence from multiple sources to continuously adapt and evolve.

HIV also has common future challenges with other areas of health promotion. Some examples include an aging population living with HIV and co-morbidities, diversifying communities affected by HIV; ongoing barriers to evidence-based health promotion due to policy and legal systems outside of health, and the increasing interaction between biomedical, behavioural and structural responses. No program can respond to these and other broader and cross-impacting issues alone. Possibly due to its early and, in some areas continuing, experience of stigma and discrimination, HIV programs tend to have a reputation of being a somewhat isolationist response within public health and health promotion. However, as a profession and a movement, all health promotion needs to engage with the interactions and synergies across the promotion of health, learn from our shared evidence and resist the siloing of our responses.

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