3. Public Health and AIDS Activism

A lot of the work of the AIDS movement in the 1980s was about the way in which HIV/AIDS and the people most affected by it were defined and the steps that needed to be taken to address AIDS. This work was done in conjunction with a range of other individuals and organisations with an interest in HIV/AIDS—most notably from within the Government and the medical profession. Kevin White and Evan Willis argue that there were three core groups competing to 'enforce their definition of the (HIV/AIDS) situation'.[1] The first of these groups was the 'inner circle' of doctors, scientists and medical researchers working in the HIV/AIDS sector. White and Willis describe the second as the 'dissenting enclave'—those non-governmental groups such as the AIDS movement who worked in parallel with the inner circle, but also challenged their scientific autonomy. The third group is the 'exoteric' body of lay-people surrounding both the inner circle and the dissenting enclave. This 'exoteric body' tends to support the knowledge and values of the inner circle, and seeks to minimise the impact of the dissenting enclave. In the case of HIV/AIDS, the exoteric body was usually people with an anti-gay, pro–nuclear-family agenda—often religious organisations or conservative public commentators. Borrowing from White and Willis, the following chapters explore the relationship between these three groups in the production of knowledge about HIV/AIDS, and in defining Australia's social and public health response to HIV/AIDS. I focus predominantly on the relationship between the medical profession (the inner circle) and the AIDS movement (the dissenting enclave), although those forming the 'exoteric body' (such as conservative churches and various journalists) also influenced the direction of discussion about HIV/AIDS at various times. The way in which HIV/AIDS came to be perceived and dealt with in Australia was largely a product of both the contest and the collaboration that occurred between these different social groups and the work of individuals who sat within both groups, such as gay men who were doctors.

As AIDS activists had attained a more credible and legitimised position within the Federal Government's response to HIV/AIDS, there was pressure on the 'inner circle' to negotiate with them. The tension this created was evident in one of the first major debates in Australia about public health responses to AIDS: the issue of HIV antibody testing.

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1   White, Kevin and Willis, Evan 1992, 'The Languages of AIDS', *New Zealand Sociology*, 7(2), pp. 127–49, at p. 127.

To Test or Not to Test?: HIV antibody testing

The first HIV antibody test—the ELISA[2] test—began to be used in Australia in April 1985. As this was some years before any effective antiviral treatments were available,[3] the arrival of the ELISA test meant that people could be diagnosed as HIV positive but were not treated for the virus. For individuals who tested positive, doctors could do little besides advising on healthy lifestyle and nutrition choices and providing ongoing surveillance of related illnesses. Doctors could try to manage the physical symptoms of AIDS-related infections when they appeared, but an early diagnosis of HIV was not likely to change an individual's long-term prognosis. Despite this, medical authorities and many individual doctors strongly advocated the HIV test, with the Albion Street Clinic in Sydney (a prominent HIV/AIDS and sexual health clinic) releasing a pamphlet that proclaimed 'A Simple Blood Test Could Save Your Life'.[4] From a medical research perspective, the ELISA test created the capacity for wide-scale monitoring of the virus. There was also a general view held by many medical professionals that knowing one's HIV status was a good thing in terms of self-care and accessing appropriate clinical services as early as possible.

For many people in the gay community, however, the reasons *not* to submit to an HIV test far outweighed the reasons for testing. As well as unease about the stress and emotional trauma that would likely be associated with a positive diagnosis, people were concerned about the discrimination they might face if they were known to have HIV. Studies conducted by the Queensland and WA AIDS councils at the time also showed that gay men were reluctant to take an HIV test because they did not trust government guarantees about the confidentiality of test results. Unsurprisingly, given that homosexuality was still on the criminal code in those States, gay men also feared persecution by authorities if they did test positive.[5] The following extract from the memoirs of an Australian man, David Menadue, describes well the tension brought about by an HIV test:

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2   ELISA is an abbreviation for 'enzyme-linked immunosorbent assay'.
3   The first breed of HIV medications—a drug known as Zidovudine (or more commonly AZT)—began to be trialled in the United States in 1986 but did not become widely available in Australia until the 1990s. Sendziuk, Paul 2003, *Learning to Trust: Australian Responses to AIDS*, UNSW Press, Sydney.
4   Ibid.
5   Bull, Melissa, Pinto, Susan and Wilson, Paul 1991, 'Homosexual Law Reform in Australia', *Australian Institute of Criminology Trends and Issues in Crime and Criminal Justice*, 29, <http://aic.gov.au>

My doctor, David Bradford,[6] pronounced, 'David, I'm sorry to have to tell you this, but your test is positive.'

So much for my friends who claimed there was no way this virus had reached Melbourne yet. So much for my general practitioner who had said several weeks earlier that the swollen glands in my armpits were probably the result of a transient infection, and that I didn't need a test for this new virus…

The test had only been available in Australia for a few months, and hardly any of my friends had chosen to be tested yet. Some were afraid to find out the result. And others couldn't see the point. As one friend put it, 'What's the value of knowing you're positive? There are no treatments, it's likely to cause you added stress, and who knows, you might suffer discrimination if people find out your status'…

A counsellor at the clinic asked who I wanted to tell the news. I was about to reply that I was sure all my gay friends would support me, when he advised caution. 'Even people in the gay community don't understand much about this virus yet. Some people may harbour real fears about catching it from you, whether that's realistic or not. Think carefully about who you tell and how you handle it.'

It was finally starting to dawn on me. This was not news that would necessarily invite acceptance, understanding or compassion. This was not necessarily the same as revealing my sexuality. Even the gay community, my support base with whom I had developed my sexual identity over the past ten years, might not embrace this news. This was about disease, infection and death. There was no telling how people would react.[7]

The issue of whether or not to encourage gay men to undertake testing became a major debate among AIDS activists—and between activists, governments and researchers. Some felt that the importance to medical research was such that the movement should advocate testing even if the health benefits for individuals were negligible. Lex Watson, President of ACON at the time, wrote in *Outrage* magazine:

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6   David Bradford was a gay man and physician. He was involved in the political and medical side of the HIV/AIDS response. Phil Carswell describes Bradford as 'a true hero, living legend' for his role in assisting people with HIV/AIDS. Phil Carswell, Personal communication, 25 October 2006, Melbourne.

7   Extract from Menadue, David 2003, *Positive*, Allen & Unwin, Sydney.

> There is little dispute that more needs to be known about the natural history of the infection, and that is what is gained through testing. As a community it is clearly in our interests to participate in such research. A strong case would need to be made for non-cooperation in such work and, in my view, subject to satisfactory confidentiality procedures existing, such a case has not been made.[8]

In spite of this, a sense of unease about the security of test results underpinned all debate. It was felt that the risks posed to gay men's social security were greater than the potential research benefits of wide-scale testing. In the same edition of *Outrage*, Phil Carswell, former President of the VAC, wrote:

> At the moment, to take the antibody test is to agree to put your name and address on a list of gay men, a list over whose future use or misuse neither you nor your doctor have ultimate control, and to risk being publicly identified as an 'AIDS carrier', which is how the media invariably (and falsely) identify Ab+[9] people. The consequences of being so identified could be unpleasant. Already in the US gay men are being denied insurance, employment and housing on the grounds of an Ab+ finding.[10]

Carswell went on to conclude that '[t]he fact is that this test is simply not a useful diagnostic tool. Its only real uses are for sampling work, to measure the progression of seropositivity in the at-risk groups, and for screening blood products.'

Both Carswell and the VAC went on to review their position on testing when antiviral treatments became available and it was demonstrated that early diagnosis could improve health outcomes for people testing positive to HIV. The line taken against testing at the time, however, was that gay men should be practising safe sex regardless of their antibody status (to protect either themselves or others) and that HIV testing should not form part of an HIV-prevention strategy. It was seen as something individuals might submit to for personal reasons, but not an appropriate basis for public health practice and therefore not something that the AIDS movement should, in principle, advocate.[11]

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8   Watson, Lex 1985, 'Antibody Testing Unquestionably Has Some Value', *Outrage*, 21 (February), pp. 5 and 7.

9   HIV antibody positive.

10 Carswell, Phil 1985, 'Gay Men Should Ignore This Test', *Outrage*, February, pp. 5–7.

11 Ibid.

Meanwhile in the clinic, I had patients coming in feeling anxious about HIV testing and worried the Government would be collating lists of people with HIV. At this stage, it was thought to be quite a rare infection, and therefore feasible that people could be basically taken out of circulation and quarantined. And during that period there had been calls from respected medical academics for quarantine, even though in other forums it was argued that it wasn't going to be viable nor necessarily the best strategy…But you've got to remember that…at that stage it was less than 10 years since homosexuality had been decriminalised. Prejudices ran very deep…So there was clearly in some people's minds, some patients, this idea that if they got tested there could be… people actually spoke about how the Nazis were able to round up Jews during the war because of information they gave in the census prior to the Second World War. So they were aware that this was a possibility. Even if it was an unlikely possibility, it was something they [thought about].

— David Plummer (2004)

Apprehension about testing was indicative of the climate of fear HIVAIDS had generated among the gay community. Concerns were magnified when, in 1985, the NSW Government proposed legislation that would make it mandatory for doctors to supply the Government with the names of all people testing positive to HIV (commonly referred to as compulsory notification legislation). This raised alarm among gay men, with many people cancelling appointments for testing or demanding their medical records be destroyed.[12] AIDS activists voiced opposition to the proposal, announcing publicly that they did not trust the NSW health authorities to retain the confidentiality of medical records. Presenting the concerns raised at a gay community meeting held in January 1985, Lex Watson stated to the media:

> We are worried about the uses to which the information could be put…It could be passed on to police or employers and we will not be cooperating with the government unless we get iron-clad, water-tight guarantees about confidentiality. If the test results are made notifiable, we will recommend homosexuals do not take them and actively campaign against them.[13]

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12   McDonnell, Dan 1985, 'Patient Panic on AIDS Law', *The Sun*, 28 September, p. 13; Green, Roger 1985, 'With Compulsion, Victims Go Underground', *The Canberra Times*, 6 September, p. 10.
13   Lex Watson cited in Sanderson, Wayne 1985, 'Gays May Refuse AIDS Test', *Daily Telegraph*, 14 January, p. 5.

Challenging Medical Authorities

The prospect of compulsory notification of HIV test results brought to the surface many of the anxieties HIV/AIDS had raised for gay men. It became a focus for fears that HIV/AIDS would lead to the reintroduction of State-sponsored surveillance of gay lives and new levels of discrimination. Certainly in the early 1980s there was every reason to wonder whether the types of 'HIV/AIDS containment' measures that would be enacted could lead to such a situation.[14]

Anxieties were eased to some extent by the introduction of anonymous testing systems such as name-coding.[15] As Bill Bowtell, advisor to the Federal Health Minister at the time, recalls:

> In Sydney it worked out really well because very quickly people like [Dr] David Cooper and [Dr] Ron Penny established relations of trust with the gay community and were able to build these long-term studies and cohorts and things. And people could know that if they gave their name and they enrolled in these studies that the doctors weren't going to publish them and misuse them—that they were honestly well motivated and that the Government wasn't going to use the names of all these HIV-positive people to detain them or arrest them or remove them from society. So it had an immensely beneficial effect because what happened very quickly was that our approach [brought] trust…trust turned into tests. People got themselves tested because they trusted the system and they could turn up for a universal, free, anonymous HIV test. They could give the name Donald Duck if they wanted to. But in those early years they could turn up and get tested and they would know that they weren't going to get sanctioned.[16]

Also key to increased confidence in testing systems was the presence of gay or gay-friendly doctors and medical clinics. Clinics run by gay doctors, or specifically catering to the gay community, had been established prior to HIV/AIDS, usually specialising in sexual health care for gay men. As such, there was

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14   Despite the fears expressed by people in the early 1980s, significant breaches of confidentiality with regards to HIV test results never eventuated in Australia and legislation to protect people living with HIV/AIDS from discrimination became part of the Federal *Disability Discrimination Act* in 1992. Cabassi, Julia 2001, *Barriers to Access and Effective Use of Anti-Discrimination Remedies for People Living with HIV and HCV*, Occasional Paper No. 1, Australian National Council on AIDS, Hepatitis C and Related Diseases, p. 6.

15   Bill Bowtell, Interview with the author, 28 May 2005; Ken Davis, Interview with the author, 4 November 2004; David Lowe, Interview with the author, 12 July 2005.

16   Bill Bowtell, Interview with the author, 28 May 2005. The one downside to this decision from an epidemiological point of view is that, in hindsight, it is not possible to measure how many times people were tested so the figures on HIV rates for the time generally have to be adjusted to account for multiple tests. I doubt, however, that many people would argue this downside means anonymous testing was the wrong decision to make at the time. Carswell, Personal communication, 2006.

a network of clinics that members of the gay community did, in general, trust. As former Director of the NSW AIDS Bureau and community activist David Lowe put it:

> In terms of trust in confidential processes…having general practitioners, like the [gay-run] Taylor Square people as an example, meant people did trust the confidentiality of the system…But I think people actually trusted the confidentiality of the results if they had it done in a place like that. Albion Street [Clinic] was anonymous. So I don't think that was a hugely substantial issue in reality. It was right that people had concerns about it, so it was an issue. But I think people generally felt comfortable about being tested in those settings. I think there was a big debate about whether people should be HIV tested or not. And I think that the main [issues] in that debate where whether knowing you were HIV positive had any relevance, what would you do?…[T]he reality was that. I would think that a very large majority living in the inner part of Sydney would have been tested within a year or two of the test becoming available. I don't have any data to back that up. That's based entirely on personal impressions. But most of my friends knew their HIV status and I can't remember many people who didn't…So I think the debate was a bit of a false debate in terms of the reality of people's lives, I suspect. But I think it was probably still a useful debate in terms of what is the most useful approach to HIV.[17]

As Lowe articulates, although there were still concerns about compulsory notification legislation, gay clinics combined with anonymous testing facilities meant that over time many gay men did elect to be tested. This did not mean, however, that the debates about testing and compulsory notification legislation were resolved or became irrelevant. Indeed, the stance taken by AIDS activists in response to the testing issue was highly significant because it established their critical engagement with medical authorities and launched a major discussion about the most effective way to respond to HIV/AIDS. The AIDS movement demonstrated its willingness to campaign against medical interventions it did not consider warranted. The support that AIDS activists received from the gay community as a whole meant that medical professionals could not afford to ignore them. If the AIDS movement was calling for people not to submit for testing then any public health regime that relied on large numbers of the affected population being tested could be undermined. While many individual doctors recognised this,[18] supporting the gay community in their rejection of

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17   David Lowe, Interview with the author, 12 July 2005.
18   These doctors also feared that compulsory legislation could lead people to avoid any contact with medical authorities, further limiting AIDS research and undermining prevention efforts.

compulsory notification legislation, there were other medical professionals who continued to reject any involvement of the gay community in the medical or public health response to HIV/AIDS.[19]

Tension between the AIDS movement and the medical fraternity had been developing prior to the testing debate. When Federal Health Minister, Neal Blewett, had set up NACAIDS, he had also established a separate committee: the AIDS Task Force. The role of the Task Force was to provide 'objective' medical advice about AIDS to the Government. Its membership included various clinical and scientific researchers and it was chaired by conservative medical academic Professor David Penington. In early 1985, the AIDS Task Force had released a report that projected between 20 000 and 50 000 Australian men were already carrying 'AIDS antibodies'. Headlines appeared in newspapers depicting these projections as reality rather than estimates: '50,000 Sydney Men Now Carry AIDS.'[20] AIDS activists felt that this was a vast overestimation. They accused the Task Force of scaremongering in a cynical gesture aimed at directing government funds away from community organisations and towards scientific research. In protest, gay men began to withdraw their support from a major AIDS research study. Convener of the Sydney AAC, Lex Watson, reported to the media that individuals had decided to pull out of the study because they were angry not only about the most recent actions of the Task Force but also because some leading medical professionals were calling for the closure of homosexual bathhouses and the cancellation of the annual Sydney Gay and Lesbian Mardi Gras.[21] Watson went on to argue that much of the division between AIDS activists and doctors stemmed from a refusal by the AIDS Task Force to allow openly homosexual representation on their board or to consult regularly with gay community representatives. Professor Penington responded to this by stating that the technical side of the AIDS issue should be left to doctors. He argued that '[i]f we are not able to address the scientific and medical problems without addressing the political problems, we won't get anywhere'.[22]

While Penington did not oppose community education about AIDS, his public statements indicated that he did not believe education and community participation should receive funding at the expense of medical and scientific intervention. In essence, Penington's views represented a commitment to a biomedical model of disease prevention that had long been the basis of public health efforts in Australia—a model that had medical testing and immunisation at its core. In the early 1980s, however, there was an emerging body of thought internationally on public health that was beginning to have influence within

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19 Green, 1985.

20 Frail, Rod 1985, '50,000 Sydney Men Now Carry AIDS', *Sydney Morning Herald*, 31 January, p. 1.

21 Bagwell, Sheryle and Leser, David 1985, 'Crisis Point in Gay, Doctor Relationship', *The Weekend Australian*, 2 March, p. 3.

22 Professor David Penington cited in ibid.

Australia. Commonly referred to as the 'new public health', this new body of thought lent some support to arguments being made by AIDS activists for a community-led approach to AIDS prevention.

'New Public Health': A political opportunity?

The original foundation of public health did not emerge from biomedicine. Eradication of contagious diseases was in the past more likely to be a matter related to urban infrastructure and social organisation. Improved living conditions, clean water and containment of sewage were key to curbing some of the deadliest epidemics of the eighteenth and nineteenth centuries—namely, cholera and typhoid. Through such measures, the idea that the physical state of humans is determined by the social and environmental world, rather than physiology alone, first gained mainstream credibility.

This perspective, however, came to be overshadowed by the discovery of microbes in the eighteenth century—a discovery that led to greater interest in the way in which germs spread from person to person rather than the social causes of ill health. 'Germ theory' of this type, along with breakthroughs in immunisation, convinced public health practitioners to favour individual-level and biomedically oriented measures, such as testing and the development of vaccines. Public health thus began to emerge as an extension of the medical and pharmaceutical industries.[23]

From the 1960s onward, however, treatment of acute illness had advanced to the point where the most critical issues facing the health system had become management of chronic conditions and disease prevention. To deal with this, governments were beginning to fund a range of alternative healthcare practices such as community-based care, physiotherapy and health promotion. As a result, the base of what was considered 'credible' medical intervention was broadening. The involvement of practitioners other than Western medically trained doctors was becoming more acceptable in the health sector. The orientation towards prevention of chronic disease meant that health was again being seen in terms of social factors. What came to be referred to as the 'new public health' approach was generated in this context.

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23   Frohlich, Katherine, Corin, Ellen and Potvin, Louise 2001, 'A Theoretical Proposal for the Relationship Between Context and Disease', *Sociology of Health and Illness*, 23(6), pp. 776–97; Lupton, Deborah 1995, *The Imperative of Health*, Sage Publications, London; Brandt, Allan 1997, 'Behaviour, Disease, and Health in the Twentieth Century United States', in Allan Brandt and Paul Rozin (eds), *Morality and Health*, Routledge, New York; White, Kevin 1996, 'The Social Origins of Illness and the Development of the Sociology of Health', in Carol Grbich (ed.), *Health in Australia: Sociological Concepts and Issues*, Prentice Hall, Sydney.

The philosophy of the new public health movement is underpinned by a 'holistic' approach to health, seeking to influence environmental and social barriers to good health as well as factors under an individual's control, such as their eating and exercise habits. The 'social orientation' of the new public health means that the role of doctors is de-emphasised and the involvement of people who are in a position to change or improve social conditions is central. Hence, community participation is a major part of the 'new public health' method.[24]

By the early 1980s, the new public health philosophy was beginning to have influence in international forums, with the World Health Organisation (WHO) adopting its principles in its 'Health for All by 2000' campaign launched at its Alma-Ata conference in 1978.[25] Australia was recruited to a group of countries that would work on developing 'new public health' models. The second International Health Promotion Conference in which these new ideas were the main focus of discussion was held in Adelaide in 1988.[26]

Alongside this growing prominence of new public health theories, a consumer health movement had been developing in Australia throughout the 1970s. During his short reign as Labor Prime Minister in the early part of the decade, Gough Whitlam had introduced a government-funded Community Health Program as well as a Women's Health Program and Medibank (the precursor to Medicare). When the more conservative Coalition came to power, with Malcolm Fraser as its Prime Minister, and all of these programs were dismantled, a number of community groups formed an alliance to lobby for their reinstatement. This collaboration, sponsored by the Victorian Council of Social Services and various philanthropic trusts, established the Health Issues Centre in 1983. The Health Issues Centre generated enough public profile to enable it to contribute regularly to media and other national forums on issues such as access to health services and equity in health care. The centre was a strong advocate for the reintroduction of Medicare and it campaigned around the issue of consumer rights in the health sector. State governments responded to such campaigns by establishing consumer complaints processes, such as the NSW Health Department's Complaints Unit set up in January 1984.[27]

In 1985, after the Labor Party had been returned to power, the Commonwealth Government set up the Better Health Commission (BHC), which was charged with following up the WHO Health for All by 2000 guidelines. The BHC recommended

24 Bates, Erica and Linder-Pelz, Susie 1990, *Health Care Issues*, [Second edition], Allen & Unwin, Sydney; Crichton, Anne 1990, *Slowly Taking Control? Australian Governments and Health Care Provision, 1788–1988*, Allen & Unwin, Sydney; Woolcock, Geoffrey 1999, A Vector of Identity Transmission: AIDS Activism and Social Movement Theory, Unpublished PhD Thesis, La Trobe University, Melbourne.

25 Crichton, 1990, p. 111.

26 Ibid.

27 Carter, Meredith and O'Connor, Debra 2003, 'Consumers and Health Policy Reform', in P. Liamputtong and H. Gardner (eds), *Health Social Change and Communities*, Oxford University Press, Melbourne.

that Australia increase spending on disease-prevention programs. This led to the establishment of health promotion divisions within each State health department and increased Federal Government funding for their programs. The Commonwealth Government also founded the Australian Institute for Health (later the Australian Institute for Health and Welfare) and the National Centre for Epidemiology and Population Health (NCEPH), both of which collected data on population health. The National Health and Medical Research Council (NHMRC) convened a public health subcommittee, and a health advancement section was established within the Federal Department of Community Services and Health. Much of the health promotion rhetoric that came out of these new agencies was similar to welfare-state policies—looking at income redistribution, housing policy and education as well as health care—and was consistent with new public health philosophies.[28]

So, concurrently with the appearance of AIDS, there was emerging support—internationally and domestically—for non-biomedical involvement in health care. This was a cultural and political opening for the AIDS movement. Certainly, among health bureaucrats and a number of allied health professionals working in preventative health care there was a growing awareness of the new public health and increasing acceptance of community involvement in health care and disease prevention.[29] Also, the Women's Health Movement, which had grown throughout the 1970s in the United States and Australia, had gone some way towards redefining the boundaries between medical experts and health consumers. Using a critique of patriarchal institutions—of which the medical system was considered one—the Women's Health Movement sought to lessen the knowledge gap between practitioner and client as a means of redressing the power imbalance. A core philosophy of the Women's Health Movement was enabling women to assume a sense of 'control' over their healthcare decision making.[30] Feminist academics also contributed to this. In particular, feminist critiques of science have been at the forefront of challenging concepts of 'truth' and 'fact' in the medical sciences.[31]

In the early 1980s, however, the new public health approach was very new. In hindsight, many people have commented that AIDS was the first real test of these new ideas because there was an organised community seeking to play a role in its prevention.[32] But at that time, neither government nor AIDS activists had

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28   Crichton, 1990.
29   Ken Davis, Interview with the author, 4 November 2004.
30   Epstein, Steven 1996, *Impure Science: AIDS, Activism and the Politics of Knowledge*, University of California Press, London.
31   Ibid.; Kehoe, Jean 1996, Medicine, Sexuality and Imperialism: British Medical Discourses Surrounding Venereal Disease in New Zealand and Japan: A Socio-Historical and Comparative Study, Unpublished PhD Thesis, Victoria University of Wellington, New Zealand.
32   Altman, Dennis 1994, *Power and Community: Organizational and Cultural Responses to AIDS*, Taylor and Francis, London.

the extensive vocabulary around consumer health and community participation that exists today. The WHO 'Ottawa Charter', which encapsulates a political and community empowerment approach to health promotion, was not published until 1986, long after AIDS activists had initiated their own brand of social/community approach to disease prevention.[33] Moreover, AIDS activists were pushing to be actively included in government and medical decision making. Their vision for community involvement extended far beyond a framework in which they would be considered just 'consumers' of health services.

The tension between activists and medical professionals about the direction of HIV/AIDS policy and practice is indicative of the fact that the new public health approach was far from universally understood or accepted. Australia has a long and successful history of disease eradication through mass immunisation, assisted by the island geography of the country, which allows for stringent quarantine regulation. In Australia, population-wide immunisation of children throughout the 1940s and 1950s meant diseases such as polio and tuberculosis became virtually non-existent by the 1970s.[34] By the time AIDS arrived in the 1980s there certainly was not broad agreement on the idea that patients or lay-people should be involved in health policy making. By initiating such a strong community response, AIDS activists were the public face of a new paradigm of thought in public health, and this presented a challenge to the existing order of the health system.[35]

The divisions between activists and advocates of traditional public health were heightened in the mid-1980s when questions began to be raised about whether HIV/AIDS funding should be directed towards a community education model or a more traditional public health approach combining scientific research and clinical measures.

The Politics of Safer Sex

In the mid-1980s the Federal Government, in a momentous move, agreed to support a community-based model of HIV prevention. This approach was adopted from a strategy paper that the Victorian AAC had devised in 1984 that articulated the need for education materials to be appropriately targeted to the community with which they sought to engage—in this case, gay men.

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33   Plummer, David and Irwin, Lyn 2004, Grassroots Activities, National Initiatives and HIV Prevention: Clues to Explain Australia's Dramatic Early Success in Controlling HIV, Paper presented at the TASA Conference, 8–11 December, La Trobe University, Beechworth, Vic.

34   Waldby, Cathy, Kippax, Susan and Crawford, June 1990, 'Theory in the Bedroom: A Report from the Macquarie University AIDS and Heterosexuality Project', *Journal of Social Issues*, 25(3), pp. 177–85.

35   Wachter, R. 1996, 'AIDS, Activism, and the Politics of Health', in Stella Theodoulou (ed.), *AIDS: The Politics and Policy of Disease*, Prentice Hall, Upper Saddle River, NJ.

The paper also stated that gay men were likely to be wary of attempts to 'educate' or dictate to them about matters of sex and sexuality from sources outside the community.[36] The Federal Government was aware of this report and accepted its findings, agreeing to fund gay community AIDS organisations to run HIV-prevention education. A cost-sharing agreement was enacted between the Federal and State governments through which the Victorian AIDS Council and the AIDS Council of NSW received establishment grants of $56 000 and $74 000, respectively. This gave the AIDS movement funds with which to create increasingly sophisticated HIV education materials and programs.[37]

The catchcry of 'safe sex'[38] came to define the AIDS era. It was this that formed the basis of community education campaigns rolled out by the AIDS councils in the 1980s, and it was a concept that came to be adopted by health promotion agencies across the world. The notion of safe sex continues to be a familiar, almost ubiquitous, expression in contemporary Western culture.[39]

The idea of safe sex was introduced to the Australian AIDS movement by American activist Michael Callen in a booklet titled 'How to Have Sex in an Epidemic'.[40] The first safe-sex campaigns in Australia were initiated as early as 1982 when the Sisters of Perpetual Indulgence, a mock order of (drag) nuns, distributed a leaflet explaining in detail exactly what safe sex entailed. The leaflet also discussed Karposi's sarcoma, pneumocystis carini pneumonia (PCP) and other illnesses and symptoms now known to be associated with AIDS.[41]

Following on from this, one of the first activities of the Victorian AIDS Action Committee (VAAC) education team was the Fantom Frangers, a community theatre act in which volunteers dressed in white 'Fantom'[42] suits demonstrated how to use condoms at gay saunas and other venues. VAAC's theatrical act, the *Safe Sex Sisters*, also carried the safe-sex message to the gay community through their 'nurse' drag shows performed at gay nightclubs.[43]

36   Ballard, John 1992, 'Australia: Participation and Innovation in a Federal System', in David Kirp and Ronald Bayer (eds), *AIDS in the Industrialised Democracies: Passions, Politics and Policies*, Rutgers University Press, New Brunswick, NJ.

37   Ibid.; Sendziuk, 2003.

38   During the 1990s, health education workers and community groups began to use the term 'safer sex' instead of 'safe sex', acknowledging that there is some risk of STI and HIV transmission involved in all sexual encounters, although this is minimal if safer-sex practices are adopted.

39   Altman, 1994.

40   Prestage, Garrett 2002, Investigating Sexuality: A Personal View of Homosexual Behaviour, Identities and Subcultures in Social Research, Unpublished PhD Thesis, University of New South Wales, Sydney; Ariss, Robert 1997, *Against Death: The Practice of Living with AIDS*, Gordon and Breach, Amsterdam.

41   Australian Federation of AIDS Organisations (AFAO) 1992, *HIV/AIDS and Australia's Community-Based Sector: A Success Story in Prevention*, Paper commissioned by the Commonwealth Department of Health, Housing and Community Services for the National HIV/AIDS Strategy Evaluation, Australian Federation of AIDS Organisations, Canberra.

42   The original Phantom was a comic-book superhero.

43   Victorian AIDS Council 1993, *A Dangerous Decade: Ten Years of AIDS*, Victorian AIDS Council, Melbourne.

The inaugural meeting of the Victorian AIDS Council on 4 December 1984 was also the launch of their first major safe-sex campaign: 'Great Sex, Don't Let AIDS Stop It.' The campaign included the VAC's first brochure on safe sex, the content of which had been modelled on a leaflet produced by the American Sisters of Perpetual Indulgence.[44] This was followed up in 1985 with a promotion developed around the slogan 'You'll Never Forget the Feeling (of safe sex)', a parody of a television commercial for Sheridan bedsheets being run at the time.[45]

> In a situation where people are really fearful and stigmatised and where people don't know what a [test] result means, everyone should assume that they are able to get AIDS…So we were running on 'use condoms'—at least for anal sex. We had [a New York produced] poster at ACON at the time, which said 'don't do rimming, don't do oral sex, don't kiss, limit your partners'. That was their first safe-sex promo. So it actually had nothing about condoms. All four recommendations were wrong and impossible. The gay community wasn't going to give up all kissing or oral sex. And a behaviour change to limit partners is in some way a lot harder to engineer than using condoms. So we were quite lucky, we went for the French line on a viral agent and that it was transmitted through anal sex to both partners…And therefore [by saying 'use condoms', we] were putting forward to Australian gay men an achievable short-term behaviour change.
>
> — Ken Davis (2005)

The approach taken to education by AIDS organisations was—and still is—based on the notion of what has been termed 'sex positive'. They deliberately sought to eroticise safe sex, using visually explicit images and commonly used language: 'fucking' not 'sexual intercourse'.[46] It was on the basis of it being too explicit that the first major safe-sex campaign of the NSW AAC was refused government funding.[47] The campaign, titled 'Rubba Me', run by Garrett Prestage, featured a drawing of two men having sex and used the words 'Rub Cocks', 'Rub Bodies', 'Use Rubbers'. The accompanying text discusses a range of safe-sex practices—jacking off, nipples, thigh fucking, wrestling, tickling, body licking, biting—and concludes with the phrase, 'If you still want to fuck or be fucked then it will be safer if you roll on a rubber'.[48] The NSW Health Commission had originally intended to fund the Rubba Me campaign, but withdrew money in February 1985 when they were shown its content. While the Bobby Goldsmith Foundation and the Gay Counselling Service provided funds that enabled it to

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44   Phil Carswell, Personal Communication, 25 October 2006.
45   Victorian AIDS Council, 1993.
46   Sendziuk, 2003.
47   Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) 1988, *1997 Report to the Minister for Health and Family Service*s, ANCAHRD, Canberra; Prestage, 2002.
48   Waldby et al., 1990.

go ahead as planned, it did spark some controversy.[49] Newspapers reported the launch of the 'Rubba Me' campaign with headlines such as: 'X-Rated Posters Mark Gay AIDS War—Homosexuals have officially declared war against the killer disease AIDS: Some homosexual groups are producing "X-rated" posters which tell gays how to have sex without dying.'[50]

AIDS activists, however, continued to develop similar campaigns, buoyed, rather than deterred, by such attention. Over time, State and Federal governments came to accept (or at least overlook) the explicit and erotic imagery of gay-oriented safe-sex materials, and most campaigns since 'Rubba Me' have been, at least indirectly, government funded. But the strong proviso remains that these materials are not to be distributed to 'mainstream' or young audiences. Unambiguous, explicit sexual detail has been deemed permissible only for gay men (who are already considered far from innocent in such matters).[51] The nature of safe-sex campaigns and materials produced by community-based AIDS organisations over the years has ranged from posters, brochures, safe-sex packs and videos to theatre, cartoons, cabarets, dance parties and 'cruising cards'. Gay Dowsett captures the depth of this work, writing:

> [Perhaps] nowhere else is it possible to see the tremendous impact of the engagement of the national HIV/AIDS policy with gay community activism than in their HIV prevention activities…It is this work, its innovation and daring, its libidinous imagery exuding homoerotic desire, that captured gay men's sexual culture and attached it to HIV/AIDS prevention in a way no public health issue has previously achieved.[52]

The community-education model adopted by the AIDS movement advocated the empowerment and support of the affected communities, based on the logic that individuals will have greater capacity to negotiate safe sex and make 'healthy' decisions if their self-esteem is high and they feel safe. Community leadership and positive messages about gay sex were central to this 'safe sex' promotion strategy. Activists used their position on government advisory bodies such as NACAIDS to promote this, while AIDS councils lobbied for funding to employ peer educators to run grassroots safe-sex campaigns.

Bill Whittaker recalls:

> [Community activists] pointed out to government that…we were the ones who knew how to do it. We were the only ones with the remotest possibility of engaging with that community and it had to be the

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49 ANCAHRD, 1998; AFAO, 1992.
50 Olszewski, Peter 1985, 'X-Rated Posters Mark Gay AIDS War', *Melbourne Truth*, 26 January, p. 13.
51 For more discussion on this topic, see Waldby et al., 1990.
52 Dowsett, Gary 1998, 'Pink Conspiracies: Australia's Gay Communities and National HIV/AIDS Policies, 1983–1996', in Anna Yeatman (ed.), *Activism and the Policy Process*, Allen & Unwin, Sydney.

community itself which was mobilised to be able to do anything effective about this epidemic. Bureaucrats sitting in health departments are not going to know how to engage with specific populations like that.[53]

The success of this community-education strategy and the extent to which gay men have adopted regular safe-sex practices are widely contested issues. Australian studies conducted in the late 1980s indicated that gay men were more likely to use condoms or other methods of safe sex following education campaigns.[54] Sexual health clinics at the time also pointed to decreasing rates of anal gonorrhoea—possibly indicative of more regular use of condoms.[55] Moreover, the incidence of new HIV infection peaked in 1984 and then began to decline. This was a faster rate of decline than was seen in other Western countries and has been cited as evidence of the success of gay-community interventions, as the rate of new HIV transmissions started to drop before government money had been made available.[56]

In the 1980s and early 1990s, however, many members of the medical community (although certainly not all, as I will discuss later) were not convinced that safe sex alone would be an effective HIV-prevention strategy and maintained that a medical model, based on extensive testing of high-risk groups, was the more scientifically valid course of action.[57] 'Safe sex' education as a public health strategy was new and untested. For many, this approach was considered too 'unscientific' to address a major disease epidemic such as HIV.

Of course, as is often the case, such criticism of the community-based education approach to HIV came in the context of limited resources. Many doctors were upset that funds were being diverted from what they considered to be the most scientifically valid approaches to public health. Activists also had their own interests in acquiring government funds. So these two competing perspectives on public health were pitted against each other, not only because they represented different views of disease prevention and medical intervention, but because each approach required money. For both groups, influence over government decision making was critical.

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53   Bill Whittaker, Interview with the author, 6 November 2004.

54   Margo, Jill 1989, 'Safe Sex Hailed as AIDS Cases Drop', *Sydney Morning Herald*, 5 June, p. 8; Warren, Matthew 1988, 'Gay Men Embrace ''Safe Sex'' Practices', *The Australian*, 26 December, p. 3; Ariss, 1997.

55   Sendziuk, 2003.

56   Plummer and Irwin, 2004.

57   Ariss, 1997.

[HIV] is still cited as the [public health] model that you should try. And whilst it's probably not possible to generate the same cohesive community mobilisation [with other issues], what it has led to is understanding that you need to talk to consumers…You see everywhere consumers involved. This is a product of HIV. And this is a tremendous benefit…You tend to just think of what we are doing in terms of numbers of people dying of HIV. But there are broader consequences, which I think [if] one's feeling pretty depressed these days, it's good to reflect on them, it's good to remember them.

— Bill Whittaker (2004)

Through their critical stance towards traditional public health measures, the AIDS movement asserted an alternative moral practice in public health. Activists emphasised the breach of civil rights and potential for discrimination inherent in 'test and contain' public health approaches, implicitly disputing the common assumption that science and medicine are, by nature, 'objective' and apolitical. The AIDS movement also brought an alternative paradigm of knowledge to public health policy. It was successful in 'normalising' an approach to public health that was not based solely on medical knowledge. Instead, HIV prevention and health promotion were reframed as community and political issues, not solely medical and scientific problems. While the AIDS movement gained some support for their actions from emerging ideas about 'new public health', formal 'new public health' models of disease prevention and health promotion, such as the WHO's Ottawa Charter, did not come into being until the latter half of the 1980s. When HIV/AIDS first emerged there was certainly no solid evidence of the efficacy of this approach and political support was tenuous. There was also enormous resistance to the involvement of lay-people from within the health sector. The AIDS movement broke new ground in initiating and demonstrating this new model of public health.

In hindsight, the community-empowerment approach to HIV prevention adopted by Australia came to be recognised internationally, including within the WHO, as a 'best practice' public health model.[58] Despite foreboding criticisms at the time that 'de-medicalising' the AIDS response could be disastrous, AIDS activists are now recognised worldwide for their role in the development of this model.

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58   AFAO, 1992.

Compulsory Testing?

Some of the more vocal critics of a community-led public health response to HIV/AIDS sat on the government-appointed AIDS Task Force. The AIDS Task Force was an advisory group established by the Federal Health Minister to prepare advice for the Government on scientific matters relating to HIV/AIDS and to suggest how best to allocate funding for research, prevention and treatment. The committee comprised practising and academic medical professionals and, as noted previously, was chaired by Professor David Penington, a haematologist working in academia and former Chair of the National Blood Transfusion Service (NBTS).

In 1984, the AIDS Task force devised a containment strategy for HIV/AIDS that would involve the establishment of wide-scale HIV-testing programs and a system of compulsory notification to the Health Department of positive results so the epidemic could be monitored.[59] This approach raised two issues. The first was the question of how such a program could be implemented in an environment where people were reluctant to present for testing. The second was what measures would or could be put in place to prevent those identified as HIV positive from further transmitting the virus. Would they be quarantined or have their actions restricted in any way?

Strict observance of clinical symptoms of illness, facilitated by patient monitoring and testing, is fundamental to Western biomedicine. This occurs at the level of individual patient care as well as for monitoring communicable diseases at a population level.[60] Once a test became available for HIV, it was logical for medical professionals to consider how best to use it to monitor and contain the virus. While most doctors considered voluntary testing for individual diagnosis as the only reasonable application of the test, there were many who advocated mandatory testing as a sound basis for a public health strategy.

The idea of mandatory testing was never considered by the Australian Government to be a reasonable public health strategy in the case of HIV/AIDS. Nevertheless, some people did take the idea seriously and it was picked up in media debate with some commentators likening HIV testing to the compulsory chest X-rays used to screen for tuberculosis in the 1950s. It was argued that as Australia had used compulsory medical screening before there could be no claims of discrimination by the gay community if it were once again adopted for

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59   Sendziuk, 2003.

60   Emke, Ivan 1992, 'Medical Authority and its Discontents: A Case of Organised Non-Compliance', *Critical Sociology*, 19(3), pp. 57–80.

AIDS. As a journalist writing in *The Age* put it: 'Compulsion is never attractive in a "rights" minded society, but we have come to accept it in many areas of public health and safety where the alternatives may be considered worse.'[61]

Some in the medical field, including AIDS Task Force Chair, David Penington, began to investigate methods by which identified 'at risk' populations, such as gay men, injecting drug users and prison inmates, could be compelled to submit for testing.[62]

Although the cost and logistics of such a venture meant the Federal Government remained opposed to the idea, the Health Minister, Neal Blewett, could not ignore the increasing attention being paid to the issue. In July 1986, Blewett invited a range of stakeholders—community activists, medical professionals and government representatives—to attend a summit, with the aim of achieving consensus on the matter. At the summit, it was agreed that testing should remain voluntary and take place only with informed consent and with pre and post-test patient counselling.[63]

The outcomes of this forum did not, however, entirely resolve the issue. In early 1987, the Victorian Government proposed changes to infectious diseases legislation that would have made testing of individuals participating in 'high risk' behaviour mandatory. The Victorian AIDS Council mounted a campaign against this, arguing that the delineation of 'high risk' behaviour was a highly subjective exercise—one that had potential to be an exercise in moral persecution rather than sensible public health. Following an intensive lobbying effort, this section of the legislation was eventually dropped from the draft bill.[64] The issue was raised again in 1988 with the release of a Federal Government discussion paper on the response to HIV/AIDS, which was essentially a draft of the First National AIDS Strategy. In response to the draft strategy, the Federal Opposition Liberal Party published an alternative discussion paper that proposed mandatory HIV testing of all people with sexually transmitted infections and those showing symptoms of AIDS. The paper also recommended diverting AIDS funds away from community education in favour of much broader testing regimes.[65]

The media latched on to this upsurge in attention to compulsory testing and it became the basis of several opinion polls. *The Age*, for example, ran a poll in which 75 per cent of respondents felt that those 'suspected by a government health officer' of being homosexuals should be required to have an HIV test and

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61 Barnard, Michael 1985, 'AIDS: A Time to Get Tough?', *The Age*, 19 March, p. 19.
62 Sendziuk, 2003.
63 Ballard, 1992.
64 Carr, Adam 1987, 'President's Report', *Annual Report*, Victorian AIDS Council, Melbourne.
65 McCauley, Carmel 1988, 'Opposition Looks at Mandatory AIDS Test', *The Age*, 1 September, p. 4.

87 per cent felt that all injecting drug users should be tested. A follow-up poll indicated that only 9 per cent of respondents thought that HIV testing should be anonymous.[66]

Public Health: 'Getting tough'?

AIDS activists railed against compulsory testing in any form because of concerns that obligatory testing in itself breached civil rights, but also because they felt that any notion of 'mandatory action' implicitly endorsed some form of forced detainment.[67] By taking this stance, however, activists and their supporters were often depicted as actively impeding public health.[68] The media regularly used the phrase 'get tough' to describe what were perceived as more serious public health measures: 'A Tougher Approach to AIDS Prevention';[69] 'AIDS: A Time to Get Tough?';[70] 'Making It Tougher in War on AIDS';[71] 'Tough Action the Only Way to Fight AIDS';[72] 'AIDS: MPs "Soft" on the Fight'.[73] Community education and support for civil rights were considered a 'soft' approach. 'Getting tough' became a euphemism for what was perceived to be the more objective, scientific approach to public health, focused mainly on wide-scale monitoring and containment of HIV-positive individuals. Perceptions on what

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66   Carney, Sean 1988, 'Support for Wider Use of AIDS Tests', *The Age*, 5 December, p. 1; Pirrie, Michael 1988, 'AIDS Experts Reject Compulsory Tests', *The Age*, 2 September, p. 10.

67   Historically, containment—or quarantine—had formed the basis of public health policy in Australia. It was a strategy used to counter many of the major infectious disease outbreaks in the early part of the century. In the early 1900s, for example, the impact of the Spanish influenza epidemic was minimised through the quarantining of international naval and passenger ships arriving in Australian waters. Those suspected of harbouring the pathogen were sent to a Commonwealth Quarantine Station. Briscoe, Gordon 1996, Disease, Health and Healing: Aspects of Indigenous Health in Western Australia and Queensland, 1900–1940, PhD Thesis, The Australian National University, Canberra, viewed 22 May 2006, <http://histrsss.anu.edu.au/ briscoe/intro.html> A series of sanatoria was established as prophylactic and curative centres for tuberculosis. Smith, F. B. 1996, 'Beating Mortality: Health Transition in Australia', *Eureka Street*, 6(9), p. 55; Crichton, 1990, p. 22. Quarantining HIV-positive people was occasionally raised as an option by some medical figures and conservative commentators. But as it became clear fairly early on that HIV was not transmissible by casual contact, the Federal Government never seriously considered it as an option as a wide-scale strategy. The option of detaining and quarantining HIV-positive individuals who 'act in a malicious manner attempting to infect others' was, however, raised by the Federal Government in its 1988 discussion paper on the national HIV/ AIDS strategy. 'AIDS Isolation Might Be Necessary: Church', *The Courier-Mail*, 15 February 1989, p. 16. Cuba was the only country in the world to ever institute mandatory quarantining of people with HIV—in 1986. While compulsory quarantine was lifted in 1994, in 2003, nearly half of the country's HIV-positive population still chose to live in sanatoriums. This might have been because conditions in the country became so poor following the collapse of the Soviet Union—Cuba's key international financial supporter—that sanatoriums provided a better standard of care and living. Hansen, Helena 2003, 'Human Immunodeficiency Virus and Quarantine in Cuba', *JAMA*, 290, p. 2875.

68   Ariss, 1997.

69   *The Age*, Editorial, 10 June 1989, p. 11.

70   Barnard, Michael 1985, *The Age*, 19 March, p. 19.

71   *The Mercury* [Hobart], Editorial, 23 November 1989, p. 8.

72   *Daily Telegraph*, Editorial, 2 August 1989, p. 10.

73   Lawrence, Tess 1989, *Sunday Press*, 25 June, p. 9.

'getting tough' involved invariably contained some form of legislative action, and many journalists tended to demonstrate great support for any form of legal measures introduced in Australia to contain HIV/AIDS.

In a number of States, laws were enacted making it a criminal offence to not warn sexual partners of one's HIV status, if HIV positive.[74] The *NSW Crimes Act* was also amended to make it an offence for 'maliciously causing or attempting to cause another person to contract a grievous bodily disease, which includes HIV/AIDS'.[75] Similar laws were enacted in all States and Territories of Australia. Further, as discussed in the previous chapter, it also became an offence in all States to make false declarations to the Blood Bank about one's eligibility to donate.

While laws such as these on one level appear to make good sense in terms of using available State powers to limit the spread of HIV, they were also enacted within a highly politically charged environment. Governments needed to be seen to be responding to the threat of HIV/AIDS and legal measures were more familiar and more politically 'sellable' than community education for gay men. For politicians in opposition, the need to 'get tough' was an easy criticism to level at the Federal Government.

In his address to the Third National Conference on HIV/AIDS held in 1988, Wilson Tuckey, the then Opposition spokesman on health, argued that in the interest of public health people with HIV should not be afforded any anonymity or freedom. The message was a direct critique of the Federal Government's support for community education, implying that the Government was going soft on AIDS because policy had been captured by AIDS activists.

Tuckey said:

> Now let's just compare that and this demand for public compassion with our attitude to others who put our health and the life of individuals in our community at risk. We have very strict quarantine and isolation laws for contagious diseases. The public has accepted that and you have been very successful politically in isolating AIDS from that point of view. There was no public policy debate that erupted as a result of Julian

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74   In New South Wales, the *Public Health Act 1991* makes it an offence if 'a person knowing that they are suffering from a sexually transmissible medical condition has sexual intercourse with another person, unless he or she has been informed of the risk in advance and voluntarily agrees to accept it'. Watchirs, Helen 2002, *Reforming the Law to Ensure Appropriate Responses to the Risk of Disease Transmission*, Occasional Papers No. 2, ANCAHRD Position Paper, Australian National Council on AIDS, Hepatitis C and Related Diseases, Canberra, viewed 15 April 2006, <http://www.ancahrd.org/pubs/pdfs/op_2_may02.pdf>
75   Ibid., p. 15.

> Beale's exposure to yellow fever[76]…We have little sympathy for those who maim or kill in acts of violence, no matter how unpremeditated they might be.[77]

While Tuckey's views are known for their extreme conservatism, sometimes bordering on the ridiculous, this quotation is still indicative of the argument circulating in public discourse that an appropriately 'tough' approach to public health had no moral engagement. Concerns raised by AIDS activists about civil or human rights were often met with the contention that measures adopted in the interests of public health were matters of science not morality. Activists were accused of dismissing scientific rationality. The need to 'get tough' was cited as reason enough to ignore the human rights concerns of the gay community.

The resistance was remarkable. There was absolutely [an] institutional resistance from the Department of Health. Quite famously, [a] Chief Medical Officer [in the early 1980s] wrote an assessment of what was going on with this disease, and he wrote: 'whatever else you can be assured of Minister, you can be sure this is not a virus.' They were immensely behind the eight ball and offered very little practical help [institutionally] in the early months of the problem. But the great resistance came from the traditional, orthodox medical and scientific establishment who had their hands on the NHMRC and those things, who believed completely, as a matter of given revelation, that they should take control of the response to the epidemic. When they realised the Government was serious about putting money and resources into it, they took a very traditional, orthodox, clinical/medical view and said we will take control of it. What they really meant was we don't believe in prevention, we believe in taking control of HIV/AIDS after the event—after the infection has occurred. And they were extremely dismissive of the view that the epidemic could be prevented. They were very supportive of the orthodox view of sanction and isolation and quarantine. They were very hostile to the involvement of people like Ita Buttrose, hostile to the idea of effective marketing and they certainly didn't believe that affected groups could or would or should take responsibility for changing and modifying behaviour.

— Bill Bowtell (2005)*

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* Bill Bowtell, Senior Advisor to the former Australian Minister for Health, Neal Blewett, Interview with the author, 28 May 2005.

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76 When a bill to amend the *Disability Discrimination Act* to include HIV/AIDS was being tabled in Federal Parliament, Wilson Tuckey explained further this example, stating: 'It is interesting that during the time that I mentioned a shadow Minister, the honourable member for Bruce (Mr Beale), came back to Australia from a yellow fever area. When he got back he was unable to produce evidence that he had been inoculated before he left. The health authorities immediately said to him that he could not travel north of a certain parallel in Australia until he had completed a quarantine period. He did not do that: he ignored their instructions. I do not support him in that because I think he was foolish.' Parliament of Australia 1992, *Disability Discrimination Bill 1992: Second Reading*, 19 August 1992, Parliament of Australia, Canberra, <www.aph.gov.au>

77 Tuckey, Wilson 1988, Address to Living With AIDS Toward the Year 2000: Third National Conference on AIDS, Department of Community Services and Health, 4-6 August, Hobart, p. 740.

Creating the 'Gay Lobby'

Alongside rhetoric about the need to get tough on AIDS, AIDS activists were referred to as the 'gay lobby'. The 'gay lobby' was presented as a powerful group of lobbyists intent on ensuring their own interests above those of the heterosexual public. Doctors argued that the 'gay lobby' was blocking scientifically proven public health measures in order to protect 'homosexual rights'.[78] This view was aired most prominently in the wake of a speech made by prominent eye surgeon Professor Fred Hollows in the early 1990s, in which he stated that he believed the 'gay lobby' had too much authority in HIV/AIDS policy making. Hollows used the word 'hijacked' to explain what he saw as the excessive influence of the gay community over government decisions.[79]

> I'll give you an example: I went into the staffroom at Fairfield Hospital once, around 1986. I was talking to one of the senior physicians there who was involved in treating people with AIDS. They all knew that I was both [a gay man] and a doctor. The Fairfield medical staffroom was really nice; it no longer exists. It was a sitting room with comfortable chairs and an open fire, newspapers, things like that. We'd often discuss issues. One of the senior physicians said to me: 'Don't you think there's a conflict of interest in the gay community being involved in AIDS?' That same theme came out time and time again. It was the theme that being gay compromises public health…It wouldn't happen for a non-stigmatised group. No-one would suggest that if you were doing medical research into diseases of children that liking children would be a conflict of interest.
>
> — David Plummer (2004)

The 'gay lobby' was regularly presented as anti-science, selfishly promoting the rights of gay men over the best interests of the general population and ignoring scientific evidence. This positioned gay men as a group of people whose opinions and actions should not be trusted.[80]

Arguments about the undue influence of the 'gay lobby' clearly hinged on negative stereotypes about gay men. But also, there was a sense that many

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78   Davis, Ken 1992, 'AIDS: The Right Unveils its Agenda', *Green Left Weekly*, no. 59 (17 June), p. 10.
79   Ibid.; Browning, Bob 1992, *Exploiting Health: Activists and Government Versus the People*, Canobury Press, Melbourne; Editorial, 'Managing the Truth on AIDS', *Sydney Morning Herald*, 8 June 1987, p. 6; Dewsbury, Ruth 1989, 'Doctors Accused of Silence Over AIDS', *Sydney Morning Herald*, 29 April, p. 7; Kent, Simon 1992, 'Fred Wants to Tell AIDS Story Like It Is', *The Sun-Herald*, 22 March, p. 15; Date, Margot 1992, 'Storm Continued Over Hollows AIDS Speech', *Sydney Morning Herald*, 4 March, p. 2.
80   Browning, 1992; Davis, 1992.

people within the medical profession did not trust AIDS activists because they felt that gay men, who had such a personal stake in AIDS policy, could not be objective when it came to public health policy.[81]

De-medicalisation of AIDS

The model of HIV prevention advocated by the AIDS movement came to be seen by some medical professionals as the 'de-medicalisation' of AIDS—a move away from 'real' public health measures. At the Third National Conference on AIDS in 1988, Dr Bryce Phillips, the Federal President of the Australian Medical Association (AMA), addressed the meeting. In his speech, he criticised the separation of the 'medical model' and the 'community education model', expressing concern that this kept medical professionals out of the loop in terms of provision of information and education on HIV/AIDS. He stated:

> The 'demedicalisation' of AIDS in Australia over the past four years must be redressed immediately. AIDS has major social and moral implications, but it is an infectious disease and the medical profession has a central role [to play] in its prevention and management. In carrying out this role the doctor has a responsibility both to the individual and [to] the community.[82]

Phillips campaigned publicly on this issue, informing an article published in *The Bulletin* magazine in April 1989, which stated: 'Australian doctors want a much greater emphasis on testing for the virus. And they want the disease to be notifiable. They see the government's emphasis on counselling and advertising as providing social solutions to medical problems.'[83]

In 1989, the AMA Vice-President, Bruce Shepherd (who went on to become AMA President in May 1990), began to campaign for compulsory HIV testing of all surgical patients. In the interests of protecting healthcare workers, Shepherd argued, doctors should have a right to know the HIV status of all their surgery patients. The debate had been fuelled further by an announcement from the Freemasons Private Hospital in Melbourne that it would refuse admission and

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81   Ballard, 1992.

82   Phillips, Dr Bryce 1988, The Role of the Australian Medical Association, Presented to Living With AIDS Toward the Year 2000: Third National Conference on AIDS, Department of Community Services and Health, 4–6 August, Hobart, p. 641.

83   Barnett, David 1989, 'Surgeons Alarmed at AIDS Risk', *The Bulletin*, 25 April, pp. 38–41.

treatment to any HIV-positive person.[84] There had also been a few cases in Sydney where people were refused surgery on the basis of HIV risk: in 1988 St Vincent's Hospital in Sydney declared it would not treat a man for heart surgery because he was HIV positive;[85] in 1989 a gay man appealed to the NSW Equal Opportunity Tribunal because his doctor would not perform minor elective surgery unless he agreed to have an HIV test.[86]

Shepherd's concerns, however, were clearly not only the health of medical staff.[87] Shepherd was convinced that HIV/AIDS policy had become captive to the 'gay lobby', leading to an overemphasis on non-medical solutions and the marginalisation of doctors from the AIDS sector. In April 1989, Shepherd announced plans for a conference on HIV/AIDS that would be 'free of politicians and lobbyists'—open only to doctors, dentists and nurses.[88] The *Sydney Morning Herald* reported Shepherd as saying 'the meeting was to redress the imbalance where AIDS was being treated politically and by legislation, but not scientifically'.[89]

Shepherd received support for his position from the President of the Australian Association of Surgeons (AAS), Dr David McNicol. Both were openly critical of the Federal Government's response to HIV/AIDS. The AMA and the AAS clearly wanted HIV/AIDS to be viewed as a biomedical problem that neither politicians nor community activists had the expertise, or right, to be involved with. The strategies of Shepherd were deliberate attempts to reduce the power of non-medical experts (in this case, the AIDS movement leadership) to participate in AIDS policy and to reassert the autonomy and control of the medical profession.

84   Dewsbury, Ruth 1989, 'AIDS Test Urged for Health Workers', *Sydney Morning Herald*, 9 March, p. 10.
85   By 1993, when the case was heard in court, St Vincent's admitted that the decision was made in the context of the ignorance and fear of AIDS that were a reality at the time. Date, Margot 1993, 'Patient With HIV Denied Surgery', *Sydney Morning Herald*, 18 January, p. 5.
86   Heary, Monica 1989, 'Gay Man Fights AIDS Test Demand', *The Australian*, 16 May, p. 7.
87   This issue had also become embroiled in tensions between the AMA and the Federal Government over the reintroduction of Medicare. The AMA vehemently opposed a national health insurance system such as Medicare. Blewett, Neal 2003, *AIDS in Australia: The Primitive Years, Reflections on Australia's Policy Response to the AIDS Epidemic*, Commissioned Paper Series 7, Australian Health Policy Institute, University of Sydney, NSW, viewed 5 May 2006, <http://www.ahpi.health.usyd.edu.au/pdfs/colloquia2003/AIDSpaper.pdf>
88   Bill Bowtell, Interview with the author, 28 May 2005; Ballard, 1992; Misztal, Barbara 1990, 'AIDS in Australia: Diffusion of Power and Making of Policy', in Barbara Misztal and David Moss (eds), *Action on AIDS: National Policies in Comparative Perspective*, Greenwood Press, New York; Dewsbury, Ruth 1989, 'AIDS Test Urged for Health Workers', *Sydney Morning Herald*, 9 March, p. 10; Sendziuk, 2003.
89   Sampson, John 1989, 'Date Set for AIDS Summit', *Sydney Morning Herald*, 10 April, p. 9.

> Blewett had to constantly keep his eye on homophobia. Homophobia profoundly underwrote everything that happened. If you remember, Blewett got into trouble because Bruce Shepherd and the AMA accused him of being gay…and accused him of having a conflict of interest…The issue there was that they didn't need to say that that was good or bad, the implication that was immediately apparent was that therefore he had a conflict of interest and that AIDS would get out of control—rather than saying having someone gay in a position like that would give insights into a difficult problem that they wouldn't have otherwise, which would actually make for better control. In retrospect, we know that that's exactly what happened. But this is what I mean—that Blewett was suffering from homophobic attacks. Homophobia was compromising their ability to do things.
>
> — David Plummer (2004)

Shepherd and McNicol were frustrated by the Federal Government's reluctance to support their call for mandatory testing of surgery patients.[90] The debate led to a very public row between them and Health Minister Blewett. At one point, Blewett instigated defamation proceedings against Shepherd, McNicol and the Australian Broadcasting Corporation (ABC) for broadcasting McNicol's suggestion that Blewett was gay. Insinuating that Blewett's sexuality needed to be questioned, McNicol was reported as saying 'the public had a right to know how AIDS policy was formed' and to know about 'the sort of people involved in administration of policy and funds to ensure there are no conflicts of interest'.[91] The suggestion was, of course, that Blewett might have a conflict of interest, or be unduly influenced by the 'gay lobby', because he was himself homosexual (at the time, Blewett was in a heterosexual marriage).[92]

The debates about HIV testing and the '(de-)medicalisation' of HIV were fundamentally a fight for influence and funding as each side sought a greater share of available government money to shape the HIV/AIDS response in their vision (as is the nature of politics). But these debates were also part of a struggle around who would or should be considered a legitimate 'expert' on HIV/AIDS.[93] As Dennis Altman has written:

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90   The proposal for compulsory testing of surgical patients was considered in some States (such as Tasmania in June 1990), but it did not come to fruition. Darby, Andrew 1990, 'Tas to Look at AIDS Laws', *Sydney Morning Herald*, 28 June, p. 6; Sendziuk, 2003.

91   Dewsbury, Ruth 1989, 'Blewett Launches Defamation Actions', *Sydney Morning Herald*, 22 July, p. 11.

92   Many years later, following his retirement from political office and some time after the death of his wife, Blewett did allow it to become public knowledge that he had begun a relationship with another man.

93   Misztal, 1990; Ballard, John 1998, 'The Constitution of AIDS in Australia: Taking Government at a Distance Seriously', in Mitchell Dean and Barry Hindess (eds), *Governing Australia: Studies in Contemporary Rationalities of Government*, Cambridge University Press, Melbourne.

In the early developments around AIDS one can see the outlines of a struggle for control, in which medical professionals, government officials, affected communities, and traditional sources of moral authority, particularly churches, vied to be seen as the 'experts' on the new disease. How AIDS was conceptualised was an essential tool in a sometimes very bitter struggle: was it to be understood as a primarily bio-medical problem, in which case its control should be under that of the medical establishment, or was it rather as most community-based groups argued a social and political issue, which required a much greater variety of expertise.[94]

Negative attitudes towards homosexuality became part of this struggle for control—evident in discourse that suggested that the 'gay lobby' could not be trusted to act in the best interests of public health. Conversely, the validity of some medical approaches to HIV prevention—such as wide-scale HIV monitoring and notification—were questioned by activists because they did not trust medical authorities to maintain confidentiality or to protect the civil rights of gay men who tested positive. In effect, it was to some extent because of prejudice against gay people that AIDS activists came to challenge medical authorities and to initiate a method of public health that challenged many biomedically oriented approaches.

Confronting science and medical authorities in this way did not, however, mean that there was a perpetually hostile relationship between AIDS activists and medical professionals. While there were some individual doctors who certainly represented and upheld the traditional authority of Western medicine, there were others who were willing to develop working relationships with activists, and indeed there were many who sat in both groups (gay men who were doctors). Developing relationships between activists and doctors was not, however, necessarily an easy process. Prior to HIV/AIDS, there had been few situations where groups of medical doctors were forced to form working partnerships, or negotiate, with the gay community and vice versa. Both groups came from vastly different social and ideological locations and there was little history of trust between them. Nevertheless, relationships between AIDS activists and the medical profession were necessary given the approach the Federal Government had decided to pursue in response to AIDS. These relationships became even more complex, however, as new medical treatments for HIV became available towards the end of the 1980s and into the 1990s.

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94   Altman, 1994, p. 26.