

4. Treatment Action

The first hope of a possible course of treatment for HIV came in the second half of the 1980s. Azidothymidine or Zidovudine (AZT) was originally developed in the 1960s for the treatment of cancer. In 1986, however, US researchers announced that it would begin to be trialled as a potential antiviral medication for HIV. This was the first clinical therapy to be developed for HIV. Before this, the only available treatment had been for AIDS-related conditions, such as antibiotics for infections. Nothing until this point had promised the possibility of forestalling the damage caused by HIV to the body's immune system. People were excited about the potential for this to be a 'miracle drug'.¹

Large-scale clinical trials had been set up in the United States to test for the efficacy and safety of AZT. In 1987, the Australian National Health and Medical Research Council (NHMRC) funded an Australian arm of the trial. It was not long after this that US trials were terminated so that people in the 'control group' of the trial, who had been receiving placebo pills, could be offered AZT. The drug was proving to be effective.² This move did not, however, translate into wide availability of the drug in Australia. Australian authorities were not prepared to approve the drug on the back of US research. AZT trials continued.

For those who had been diagnosed HIV positive in the 1980s, AZT was the first hope of a lifeline and, although people were cautious, there was much hype about the possibilities. Knowing that the drug was attainable in the United States but not Australia was immensely frustrating for some people with HIV/AIDS.³

When it became clear that it could be a long time before AZT would be widely available in Australia, frustration and anger became driving forces for the AIDS movement. Activists agitated for AZT to be immediately approved for wide distribution in Australia. At the time, only those enrolled in the Australian trial had access to the drug, and limited government funds meant this number was small. The high cost of AZT was also proving prohibitive. Even if the drug was more widely available, it was estimated that a year's supply would cost an individual about \$10 000.⁴

1 Sendziuk, Paul 2003, *Learning to Trust: Australian Responses to AIDS*, UNSW Press, Sydney.

2 Ariss, Robert 1997, *Against Death: The Practice of Living with AIDS*, Gordon and Breach, Amsterdam.

3 Ibid.

4 Ibid.

The issues raised by the AZT trial marked the beginning of the AIDS movement's engagement with the pharmaceutical and medical systems in Australia. Activists in Canberra began to campaign for AZT to be added to the Federal Pharmaceutical Benefits Scheme (PBS) as well as for its immediate approval by the Therapeutic Goods Administration (TGA).⁵ At the State level, ACON organised a rally in November 1987 to demand that the NSW State Government provide extra funding for the immediate expansion of the existing AZT trial.⁶

According to Don Baxter:

A key moment in ACON's history, and in the history of the epidemic really, was the demonstration that ACON organised in November '87 for the provision of AZT, outside Parliament House when [Peter] Anderson was still the [NSW Health] Minister. They were trying to get away with limiting provision of treatments because they were too expensive. I think we demonstrated then that they were not going to get away with those sorts of decisions.⁷

We were hearing reports of AZT, a new drug that was being trialed in the States, and these refocused [his] thoughts on America, regenerating in him the old illusion that if only he were in a different place he might somehow discover himself to be a different person...AZT sounded more promising than the do-it-yourself cures of the AIDS underground: but the more he thought about it, the more both AZT and America itself receded into an unattainable dream...We could hardly afford the airfare, let alone the obscene price that Burroughs Wellcome found it proper to charge for their new drug. And even if we made it to New York, there was no apartment, no family, no medical insurance to come home to. At the end of the road there would be at best a public hospice. That prospect shattered the fantasy.

— John Foster*

* Extract from Foster, John 1993, *Take Me to Paris, Johnny*, Black Inc., Melbourne—a memoir by John Foster of his lover's life and death from AIDS.

Medical Dominance and Treatment Action

When Talcott Parsons coined the term the 'sick role' he was making the point that in modern society being sick is a socio-cultural experience as much as it is a

⁵ Ariss, 1997.

⁶ Ibid.

⁷ Don Baxter, Interview with James Waites, 26 November 1993, Oral History Project: The Australian Response to AIDS, TRC 2815/75, National Library of Australia, Canberra [hereinafter NLA].

physiological one. According to Parsons, once a person is diagnosed as ‘sick’ they are ordained with a particular set of expectations, including passive acceptance of their doctor’s advice. The sick role implies that patients are required to be compliant and cooperative in the service of getting well.⁸ Those who do not adhere to such a role risk acquiring labels of ‘deviancy’ or ‘insanity’.

The modern medical system has only limited room for the active involvement of lay-people. Western-trained doctors have an official mandate to define the nature of health issues and determine treatment regimes. This is supported by the state through licensing structures that regulate who may and may not identify themselves as a legitimate health professional. There is a common acceptance that those who are not trained within the discipline of Western medicine are not eligible to contribute to medical knowledge. That is, those who are not qualified according to orthodox Western medical tradition—or are not compliant with it—are given little authority to comment on ‘health issues’ considered by the medical profession to sit within its domain.

Evan Willis describes the history of the Australian health system as one of competing tensions between occupational groups—the dominant group being medical doctors.⁹ Midwives, for example, were once considered the primary ‘experts’ in relation to pregnancy and childbirth. In more recent history, however, their role has been marginalised by obstetricians. The medical profession increasingly dictates the role that midwives may legally play in child-birthing. This shift has not occurred because midwives are less capable than obstetricians of successfully delivering a child in the majority of circumstances. Rather it has been a process of one more powerful profession (in terms of financial and ideological power) staking a claim over the occupational territory of another. The knowledge and experience of midwives are positioned as a less sophisticated and reliable form of knowledge than that of Western medicine; patients are directed away from midwifery services towards GPs and obstetricians.¹⁰

The point being made by Willis is that the dominant role of doctors in matters pertaining to the body, health and illness is historically grounded. Medical knowledge is not innately more appropriate for understanding issues such as childbirth than that which informs other healing occupations. Nor is it the only way of assessing such issues. Indeed, childbirth was never considered a medical issue before it was framed as such by Western medicine.¹¹ This is not to say that

8 Crossley, Michele 1998, “‘Sick Role’ or ‘Empowerment’”? The Ambiguities of Life with an HIV Positive Diagnosis’, *Sociology of Health and Illness*, 20(4), pp. 507–31.

9 Willis, Evan 1989, *Medical Dominance: The Division of Labour in Australian Health Care*, Allen & Unwin, Sydney.

10 Ibid.

11 I do not intend in this discussion to argue that obstetrics and modern medicine have not contributed to improving the safety of childbirth for both mother and infant. The point, rather, is that it is relatively

medical knowledge is irrelevant to health or that medical advances have not improved the physical condition, and extended the lives, of many individuals. But medical doctors gained the authority and autonomy that they currently have through the political and socioeconomic history of the medical profession in relation to other groups and the dominant position that science and medicine have acquired in the modern West.¹²

In the 1980s, the concept of 'consumer participation' or 'community involvement' in the medical system was very new. Recalling her impression of the medical system in the 1980s, a former advisor to Federal Health Minister Neal Blewett, Kate Moore, writes:

In my early experience of the health system, I saw it as a fortress surrounded by a moat—with all the drawbridges drawn up to prevent outside influence or scrutiny. The only way in or out of the edifice was over a drawbridge marked 'patient', where the role was ascribed as being passive and compliant. Any attempt to cross the drawbridge in other ways was met with outright hostility. Participation by consumers through the more conventional means we are now used to was just not possible then—so it was necessary to bring down the drawbridges through noisier and perhaps more confrontational methods.¹³

In terms of the extent to which they 'drew down the drawbridges' of the medical establishment, the AIDS movement has been one of the most successful community health movements in Australia. This is especially so in relation to the role the AIDS movement played in instigating systematic changes to the structures by which pharmaceuticals are trialled and approved for distribution in Australia, and in increasing the involvement of lay-people within the health sector as a whole.

As 'treatment action' around AZT began to expand, the AIDS movement made demands on both the Government and the medical profession in several key areas. First, activists wanted the Government to fund trials of new HIV therapies and to put more money into existing trials.¹⁴ Second, they wanted the time it

recently that childbirth has come to be considered a medical process rather than a natural stage of human development. The high degree of medicalisation has excluded midwives from the process. In the majority of circumstances, midwives would be just as capable as a medical doctor of seeing through a safe pregnancy and delivery. Wearing, Michael 2004, 'Medical Dominance and the Division of Labour in the Health Professions', in Carol Grbich (ed.), *Health in Australia: Sociological Concepts and Issues*, Pearson, Sydney, p. 276.

12 Ibid.; Willis, 1989.

13 Moore, Kate 2006, 'Consumer Participation: A Personal Reflection', *Health Issues*, No. 89, pp. 14–17, at p. 15.

14 For example, in early 1990, ACON began lobbying the Government for greater commitment to testing DDI, a drug that was showing promising results in US trials—particularly for people who were intolerant of AZT (which could produce intense side effects) or for whom AZT was no longer working. Whittaker, Bill 1990, Treatment Issues—Updates on AZT and DDI, Letter to members of the Australian Federation of AIDS Organisations from the National President, 25 June.

took for drug therapies to be approved for use in Australia to be drastically shortened. On these two points, the major targets of treatment activism were the Therapeutic Goods Administration (TGA) and the Federal Health Minister. Alongside this, activists also made demands of medical research institutions and individual doctors involved in the trialling of new HIV medications. They wanted greater accountability to people living with HIV/AIDS—and to the community in general—in terms of the way in which they conducted their research. Activists argued that the complex legal and ethical issues raised by HIV/AIDS and the processes of clinical trials necessitated the participation of a wide range of stakeholders, particularly people who were most affected personally by the outcomes of such trials. Activists also took charge of accessing their own knowledge and information about HIV medicine.

AIDS Knowledge, AIDS Action

Although the AZT trials brought ‘treatment action’ to the forefront of AIDS activism, it was not the first time the AIDS movement had challenged medical dominance. The willingness of activists to question medical intervention was evident throughout earlier debates about HIV testing. But also, from the beginning of the 1980s, activists had regularly disseminated detailed medical information about AIDS to the gay community through the gay press and community-produced brochures. As such, activists had a high level of medical knowledge and were accustomed to controlling the flow of medical information to the gay community. Rather than waiting for health information to be provided to them from medical authorities, activists researched, produced and disseminated clinical reports about HIV/AIDS. Activists did not see ‘medical knowledge’ as an area outside their domain. Nor did they view medical authorities as having an inherent right to control such knowledge and information.¹⁵

In July 1981, the gay community newspaper the *Sydney Star Observer* published a short article about cases of pneumonia that had been detected among gay men in the United States.¹⁶ Following this, the local gay media released new information about the virus as it emerged from the United States. The first lengthy article was published in *Campaign* magazine in April 1983, just after the first AIDS case

¹⁵ Adam Carr was a journalist who, from the early 1980s, began to write articles on HIV/AIDS for the gay press. Carr read all the medical literature he could find on HIV/AIDS and followed all information being published through US sources, translating this into language that would be easily understood by the general public. Carr is regularly cited as one of the key sources of information about HIV/AIDS for the gay community throughout the 1980s and 1990s. Many of these articles can still be viewed on Carr’s personal web site: <<http://www.adam-carr.net/>>

¹⁶ Ariss, 1997.

had been detected in Australia. As information in the mainstream media in the first few years of the 1980s was minimal, AIDS reporting in the gay press was the primary source of information about the disease for many people.¹⁷

We had people that had respect for evidence early on—epidemiology. And the trouble was our level of epidemiology at that stage was pretty much gossip. But we managed to make it so that it was more reliable gossip. When you can't do double-blind clinical trials, but what you've got is a network of gay GPs who have seen guys every day and have talked to each other and are talking to you, that intelligence has to be treated, I think, the same way as the classic Cochrane type study—in context. If we had waited for the real hard evidence to come by, we would have all become infected, if not dead. We had to make certain judgments at times based on what we knew and what we felt. It was intuitive stuff but a lot of it was gut right—the evidence backs [it] up in some cases rather than the other way around. But I think it's understandable at the first stages of the epidemic where there is panic—not only panic personally and psychologically but socially.

— Phil Carswell (2005a)

In the very early 1980s, AIDS activist also found themselves supplying information to general practitioners. At this point, there were only a small number of scientific publications on AIDS worldwide.¹⁸ Virtually the only AIDS reporting read by some members of the medical profession came from the gay-community media and AIDS activists. The absence of alternative sources also meant the Government relied on information from AIDS activists. This provided activists with an opportunity to play a formal role in the AIDS response.¹⁹

When AZT and the first antiviral medications became available, AIDS information published in the gay press became much more detailed and focused on providing information about treatment options. A number of treatment-specific publications came into being. In 1988, activist Terry Bell established the *AIDS Advocate*, a treatment information and advocacy newsletter. Bell's philosophy was one of empowerment through education. His objective was to ensure people with HIV had enough knowledge to be able to ask questions of doctors and determine their own course of treatment. In part, this was a strategy

17 David Plummer, Interview with the author, 30 August 2004; Ariss, 1997; 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; Ballard, John 1989, 'The Politics of AIDS', in Heather Gardner (ed.), *The Politics of Health: The Australian Experience*, Churchill Livingstone, Melbourne.

18 See, for example, Marx, Jean L. 1982, 'New Disease Baffles Medical Community: "AIDS" is a Serious Public Health Hazard, but May Also Provide Insights into the Workings of the Immune System and the Origin of Cancer', *Science*, 217 (13 August), pp. 618–22.

19 David Plummer, Interview with the author, 30 August 2004.

of shifting the power imbalance between doctors and patients. But also, Bell was aware that, at the time, many GPs did not have a great deal of knowledge about HIV treatment themselves, so patients simply had to do their own research.²⁰ Alongside this, another treatment information magazine, *Talkabout*, began to be published in 1988 by the organisation People Living With HIV/AIDS (PLWHA) in New South Wales. Then, in the early 1990s, the national peak body, AFAO, established a treatment information program with assistance from Federal Government funding. The project produced a regular publication, the *HIV Herald*, which was distributed nationally. The *HIV Herald* provided information about available treatments as well as continuing and upcoming drug trials. AFAO also began work with the National Association of People With AIDS (NAPWA) to produce *Positive Living*, a publication that was first released in 1995 and quickly became one of the major sources of information about HIV treatments in Australia. Publishing treatment information such as this was intended to endow people with enough knowledge to determine their own course of HIV treatment. It also encouraged people to adopt an inquisitive and critical approach to medicine and science, and to the advice of their doctors. While it might seem like an obvious initiative for activists to take in hindsight, there was no real precedent in Australia at the time for patient groups taking charge of medical advice. Certainly, the notion that patients should be encouraged to take a critical approach to their doctor's advice was uncommon.²¹ As activist Ian Rankin observed: 'Some issues such [as] how a patient should go about choosing a GP or their right to have a say in their own treatment had never been [debated] before in Australia.'²²

Coordinating Treatment Action

Late in 1990, the then Federal Minister for Health and Community Services, Brian Howe,²³ agreed to make AZT more widely available through clinical trials. Previously in Australia people had been permitted to enter trials for AZT only if their T-cell/CD4²⁴ cell count was less than two hundred. Following an ongoing campaign by activists, Howe changed the regulations to enable people with a

20 Ariss, 1997.

21 Hurley, Michael 2001, *Strategic and Conceptual Issues for Community Based, HIV/AIDS Treatments Media*, Researchers in Residence Program, Working Paper 3, Australian Federation of AIDS Organisations, Newtown, NSW, and Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne; Ariss, 1997.

22 Ian Rankin, Interview with the author, 26 July 2004.

23 Brian Howe replaced Neal Blewett as Federal Health Minister following the federal election in February 1990 in which the Australian Labor Party retained government.

24 HIV infects cells in the immune system and the central nervous system. The main cell HIV infects is called a T helper lymphocyte (T-cells). The T-cell is a crucial part of the immune system as it coordinates the actions of other immune system cells. A large reduction in the number of T-cells seriously weakens the immune system. Progression of HIV can be monitored by measuring the number of T-cells in a person's blood.

cell count of less than 500 to access AZT trials, bringing Australia into line with the model being used in America at the time.²⁵ This allowed many more people to access AZT, but only if they were part of the trial.

Government even back then was reactive largely. And the non-government actors set the agenda. What you found in the Health Department and among politicians was an openness to doing the right thing. But they were looking for ideas and they went to the non-government sector for suggestions. You've got to realise that there was almost no research or information either on the social class of people affected or the epidemic. In those early days we didn't even know a virus caused it. It was all speculation. So the research was lacking, in that formal scientific sense. But certainly there were very clear sources of information from the communities themselves. They knew how it worked. That's something that's different now. Now government tends to think they know it all. They can just do a literature search. Whereas back then they didn't claim to know it all and they listened. They wanted to know the 'street talk', how it all worked.

— David Plummer (2005)

In terms of making AZT available to people outside clinical trials, there were two major delays. First, the company that produced AZT, Wellcome, needed more information than it had available at the time for its submission to the TGA. Also, the TGA committee that made the final assessment, the Australian Drug Evaluation Committee (ADEC), met infrequently and lacked mechanisms to respond quickly to new evidence. So even after submissions were received by ADEC there were no guarantees about the time the committee would take to process them. Wellcome finally delivered their submission with new data to ADEC on 31 May 1990. The AFAO met with the Health Minister, Brian Howe, in the same month to ask him to push ADEC to consider the Wellcome application as a priority issue. At the ADEC meeting on 26 June 1990, however, the submission was not even discussed.²⁶

This angered people within the AIDS movement and the issue came to a head in 1990 when, at the National AIDS Conference, demonstrators stormed the stage while Howe was delivering the opening address. Activists demanded Howe set in motion a system to 'fast-track' experimental HIV drugs; they then pre-empted the rest of his speech by officially declaring the conference open before he was

People are considered asymptomatic if their T-cell/CD4 count is greater than or equal to 500 cells/mL. AVERT 2005, *The Different Stages of HIV Infection*, AVERT web site, viewed 20 March 2006, <<http://www.avert.org/hivstages.htm>>

25 Sendziuk, 2003; Whittaker, 1990.

26 Whittaker, 1990.

able to.²⁷ As Robert Ariss writes: 'Media coverage of the event presented images of a new Federal Minister of Health, Brian Howe, humbled before a crowd of shouting men and women sporting T-shirts demanding, "Cut the Red Tape".'²⁸

Alongside this, a coalition of community AIDS organisations was established. Calling itself the AIDS Treatment Action Committee (ATAC), the committee was an alliance of, among others, ACON, VAC, People Living With AIDS (PLWA) Victoria, the AIDS Action Council of the ACT, PLWA ACT, National People Living With AIDS Coalition (NPLWAC), AFAO and the AIDS Coalition to Unleash Power (ACT UP).

Members of ATAC were politically astute lobbyists. They used very simple but striking and consistent messages in their media statements. The cover page of all their media kits included a cartoon depicting a man watching television, a look of enlightenment across his face. The caption reads: 'It suddenly dawned on him, lives could be saved if he approves HIV treatment faster.'²⁹ They campaigned on a number of fronts, organising community protests as well as engaging at a bureaucratic level. For example, ATAC prepared a cost-benefit analysis arguing the case for early provision of HIV treatment in economic terms. The report, which they presented to the Federal Government, concluded that 'early access to available treatments combined with vigorous investment in treatment research will lead to a significant lessening of the direct and indirect monetary costs and the human and ethical costs of HIV/AIDS'.³⁰ ATAC also conducted street demonstrations and grassroots campaigns. At the 1991 Sydney Gay and Lesbian Mardi Gras parade, ATAC led a contingent of more than 100 people dressed in black T-shirts adorned with a pair of red lips ingesting an AZT capsule.³¹ ATAC was good at integrating their political lobbying with gay-community education. They produced a community information kit about AIDS treatments and organised regular public forums at community, social and sporting events.³² The various organisations involved in ATAC also contributed their own resources to the campaign. For instance, the VAAC produced the first guidelines on ethical standards in HIV/AIDS clinical research, articulating the changes they wanted to introduce.³³ Also, in 1991, ACON established an AIDS Treatment Importing Scheme. This scheme exploited a 1990 amendment to

27 Woolcock, Geoffrey 1999, *A Vector of Identity Transmission: AIDS Activism and Social Movement Theory*, Unpublished PhD Thesis, La Trobe University, Melbourne.

28 Ariss, 1997, p. 186.

29 AIDS Treatment Action Committee (ATAC) 1991a, National Media Kit, July, ATAC, Sydney.

30 AIDS Treatment Action Committee (ATAC) 1991b, *The Economic, Social and Ethical Costs of HIV/AIDS*, Adapted from AIDS Council of NSW 1990 'The Trialing, approval and marketing of treatments and therapies for HIV/AIDS and related diseases: a policy document' ACON, Sydney, ATAC, Sydney.

31 Ariss, 1997.

32 Andrews, Dean 1991, 'HIV and AIDS Treatments: Action Campaign Gears Up', *Sydney Star Observer*, 28 June, p. 1.

33 Phil Carswell, Personal Communication, 25 October 2006.

the *Australian Therapeutic Goods Act* that allowed individuals to import, for their personal use, pharmaceuticals not yet approved in Australia provided they obtained a doctor's prescription. ACON's scheme assisted GPs to write appropriate scripts, and instructed people with HIV how to order drugs from overseas suppliers. The scheme also arranged bulk postage of drugs to reduce postage costs (which were often very high).³⁴

Treatment activism began to broaden beyond AZT to encompass research related to all HIV treatment. For example, in late 1988, news from the United States indicated a derivative of egg lipids could be effective as an HIV antiviral therapy. In the United States, the treatment—called AL721³⁵—was accessible because it fell under the 'alternative' therapy banner. Following a campaign by US activists, the American Food and Drug Administration (FDA) had made AL721 available as a food supplement rather than a pharmaceutical. The Albion Street Clinic in Sydney announced that it would undertake a trial of AL721 early in 1989, and put out a public notice to people warning them not to purchase the drug from overseas until it had been tested in Australia. Before the trial had commenced, however, the director of the Albion Street Clinic, Dr Julian Gold, announced that due to new evidence indicating the inefficacy of AL721 the trial would probably be cancelled. AIDS activists were angry that this decision was made without their notice, leading them to organise a more focused campaign around medical institutions' unwillingness to incorporate community interests into their decision making.³⁶

The media campaigning that accompanied this was not, however, always successful. For example, a press release put out by the organisation People Living With AIDS (PLWA) NSW in May 1989 asserted that clinics had a moral obligation to base their research priorities on community need and social responsibility.³⁷ The media did not respond to the press release as activists had hoped. Instead, the angle taken was that PLWA was foolishly, or desperately, clinging to ineffective treatments and should listen to the experts. The press quoted researchers who argued clinical trials were the fastest means to evaluate the efficacy and safety of drugs and that weakening restrictions placed on drug trials could allow unsafe drugs onto the market, with potentially disastrous outcomes.³⁸ Such criticism, however, did not deter activists. In fact, media attention such as this was indicative of the level of debate the AIDS movement generated around the issue.

34 Sendziuk, 2003.

35 For more information on AL721, see Antonian, L., Shinitzky, M., Samuel, D. and Lippa, A. 1987, 'AL721, A Novel Membrane Fluidizer', *Neuroscience and Biobehavioral Reviews*, 11(4), pp. 399–413.

36 Ariss, 1997.

37 Ibid.

38 Ibid.; Epstein, Steven 1996, *Impure Science: AIDS, Activism and the Politics of Knowledge*, University of California Press, London.

ACT UP Australia: Action = life

One of the more radical activist groups that formed part of the Australian AIDS movement was the AIDS Coalition to Unleash Power (ACT UP). American activist and playwright Larry Kramer first started ACT UP in New York in 1987. Following this, chapters of ACT UP were established throughout the world. Although ACT UP chapters generally maintained ties with each other, the organisation always remained resolutely ‘grassroots’ and informal with no centralised body and only limited formal structures. ACT UP was characterised by its distinctive form of cultural activism and use of symbols—the most prominent being the pink triangle, a symbol used internationally by the gay liberation movement reminiscent of the patch homosexuals were forced to wear by the Nazis during World War II, accompanied by the slogan ‘SILENCE = DEATH’.³⁹

At that time we were giving about one major demonstration a month, and the way it was handled was there would be an issue chosen and we’d plan the demonstration for three or four weeks and then we’d give the demonstration. It was happening about once a month. The first one was the one at Kent Street about AZT availability. The next demonstration in May was at Parramatta Gaol about prisons and condoms and...[NSW Minister for Corrective Services Michael] Yabsley’s mandatory testing bill, and there was a big crisis in prisons happening at that time and all that sort of stuff.

— Bruce Brown (1991)

The first Australian chapter of ACT UP formed in Sydney in April 1990. Many people involved in this first group were already participants in the AIDS movement. But ACT UP also attracted people who sought a new, more militant direction to their activism. ACT UP created opportunities for people who had not been integrated into the structures of the AIDS councils or other organisations to participate in the AIDS movement.⁴⁰

ACT UP’s first Australian street demonstration took place in April 1990. The protest was held outside the Commonwealth Health Department in Canberra where the offices of the TGA were located. Protestors demanded ADEC release AZT for use in the early stages of HIV, rather than when T-cell counts were lower.⁴¹ The demonstration received extensive television coverage, particularly

³⁹ Epstein, 1996; Woolcock, 1999.

⁴⁰ Ariss, 1997.

⁴¹ Brown, Bruce 1991, Acting Up Down Under (ACT UP Campaign Sheet), AIDS Coalition to Unleash Power, Sydney, [paper held at the Noel Butlin Archives, Ref. H3N/12, No. 174/8].

its street performance of deathly Grim Reapers wearing 'ADEC' labels, theatrically refusing to give AZT capsules to people with AIDS. A protest 'die-in' was also staged on the pavement and there was an attempt to storm the ADEC offices.⁴²

As Bruce Brown recalls:

The repercussions of that first demonstration were that ACT UP gained this tremendous self-esteem...I think ACT UP's breakthrough is that, whether or not ACT UP and AIDS issues are gay rights issues per se, they are often perceived as such, for any organisation which...was gay driven, had never received that kind of publicity in Australia. And we had this breakthrough in that ACT UP was getting regular mainstream publicity, and this was something new to a lot of activists to have that sort of success.⁴³

ACT UP played an important role in the overall landscape of AIDS 'treatment action', largely because of its skill in attracting media attention. The dramatic use of theatre and imagery, along with confrontational actions, worked well with the mass media and most ACT UP events received coverage.⁴⁴

One of the larger ACT UP protests was staged in Sydney in 1990 to coincide with the Sixth International Conference on AIDS. The conference was being held in San Francisco and American chapters of ACT UP had organised a 'takeover' of the main meeting hall.⁴⁵ Anticipating that there would be wide-scale international media attention on HIV/AIDS because of the conference takeover, Australian chapters of ACT UP staged a concurrent protest outside the American Consulate in Sydney. This achieved high-profile media attention.

According to Bruce Brown:

[Like] many other ACT UPs in the world [we planned] to protest at the American Consulate concurrent with the march in San Francisco, to protest the HIV travel restrictions that the American INS [Immigration and Naturalization Service] enforces...[This] was really ACT UP's watershed, it was a kind of galvanizing thing where we really gained our reputation and our visibility.⁴⁶

The confrontational, anger-driven tactics of ACT UP often generated tension between it and other sections of the AIDS movement. Many people felt ACT UP was simply unnecessary in Australia where activists were already included in

42 Ariss, 1997.

43 Bruce Brown, Interview with Martyn Goddard, 7 June 1992, Oral History Project: The Australian Response to AIDS, TRC 2815/6, NLA.

44 Woolcock, 1999.

45 Ariss, 1997.

46 Bruce Brown, TRC 2815/6, NLA.

government decision-making structures. There was a belief that ACT UP was an American import—a militancy that was necessary in the era of Reaganism but counterproductive in the context of Australian politics. They also criticised ACT UP for attacking some individuals within government or other agencies who were generally supportive of the AIDS movement. The tension, however, came from both sides. ACT UP's position was that the AIDS councils were an extension of government bureaucracy and not adequately reflective of the needs of people with AIDS. ACT UP activists felt that the non-confrontational politics of the broader AIDS movement kowtowed to government interests. They wanted to harness feelings of anger around HIV/AIDS, creating a more direct-action style of political demonstration.⁴⁷ In hindsight, it is probably fair to say that the two styles complemented each other well despite tension at times, and indeed there were many activists who were members of both the AIDS Councils and ACT UP.

ACT UP—FIGHT BACK—STOP AIDS was our chant for all occasions at full voice with whistles blaring. ACT UP is a direct action group that grew out of anger and inaction. We were not silent. But we were not an educational unit. We didn't see ourselves addressing safe sex education campaigns ('keeping negatives negative' as some of us saw it). We did not write reports or ask for funding costs. We used language that was provocative and often controversial. 'Murder' for example, was oft [sic] used. We targeted individuals. We also tried to re-claim some of that language, calling ourselves militant queers, taking back power and pride when we could. We sought and encouraged press coverage. We were loud. We were also an 'issue based' organisation in that we held actions or zapped offices and government departments in relation to a particular issue or target. We planned immediate and topical action and reactions. Identify. Do. Then on to the next one. Bang. We didn't always fully regard the feelings and reactions of those around us, to say the least, or always plan too many steps into the future, and we got a lot of criticism over the [effects] we caused for some people. This was quite legitimate criticism in many cases, but was something we saw as a necessary, a legitimate part of our Modus Operandi.

— Ken Basham*

* Basham, Kenn 2006, 'Speech given at the "Reflections" Exhibition at the Canberra Museum and Gallery 8 December 2004', in Ian Rankin (ed.), *AIDS Action! A History of the AIDS Action Council of the ACT*, AIDS Action Council of the ACT, Canberra.

47 Woolcock, 1999; Goddard, Martyn 1993, 'Across the Great Divide', *National AIDS Bulletin*, December 1992 – January 1993, pp. 15–17; Ariss, 1997.

I've never known an issue to scare health ministers as much as AIDS. I remember working with Labor Ministers, down in Victoria and nationally, good lefties (Brian Howe and Caroline Hogg and her successor, Maureen Lyster) and being in meetings and they were quite scared because there was an ACT UP demo outside. Not only because of the power of performance over media—the media was all over this disease, it was part of this disease—but the counter media was also, the theatre and the nature of ACT UP and its wit and sharpness was something that was very post-modern. That dynamic was really fascinating to watch. They really had political power, even though they were a very small group. They were visible and they were intelligent...I think the politicians were very much intimidated by ACT UP. (We never told them, we didn't want them to get swelled heads!) Besides [ACT UP's] fundamental role in the epidemic was different. ACT UP in America was necessary, it was actually vital. If ACT UP hadn't been in America it would have been crazy. ACT UP in Australia, half of them were public servants, half of them were employed by the health department. Our relationship was different. It wasn't 'you murderers'. They knew that we weren't bad people. They were making points to the media and the general community more than to us as the enemy. So that was really interesting.

— Phil Carswell (2005a)

Treating the System: The Baume Review

In November 1987, two days after ACON had held its demonstration to demand greater funding for AZT trials, more money was provided by the NSW Government to allow an extra 20 participants into the AZT trial. This of course did not solve the problem of an exceedingly slow drug-approval process in Australia—an issue that was escalated in the minds of activists in March 1990 when the American FDA approved AZT for general prescription in that country.⁴⁸

Endorsement by the FDA or other overseas authorities does not ensure a drug will be made available in Australia. Rather, all new medications must undergo an Australian-specific trial process and gain TGA approval. The TGA, with its stringent testing regimes, was set up in response to the infamous 'thalidomide scandal' of the early 1960s in which an approved drug turned out to have devastating side effects on children whose mothers had taken it while pregnant (as thalidomide was prescribed for morning sickness, there were many such cases). While TGA regulations were put in place for obviously sound reasons, it did mean that in the 1980s the process for approving new drugs took two to

⁴⁸ Sendziuk, 2003.

three years and required significant financial investment from pharmaceutical manufacturers. Given the relatively small Australian market for pharmaceuticals, many companies were not willing to make that investment.⁴⁹

Communication between AIDS activists in Australia and those in the United States meant people in Australia were well aware of the availability and efficacy of AZT. For Australian activists, there did not seem to be any convincing reason why it should not be similarly available in Australia when it was clear many hundreds of people would die (and were already dying) from AIDS while waiting for TGA approval. Australian activists were also inspired by the US treatment-action campaign when activists had been successful in speeding up the FDA approval process for HIV drugs.⁵⁰

Towards the end of 1990, in response to activist demands, Health Minister Brian Howe directed the Australian National Council on AIDS (ANCA) to facilitate an inquiry into how best to hasten the process of drug approval in Australia. The ANCA report was completed in December 1990. It made 37 recommendations that focused on fast-tracking experimental drugs. It also highlighted impediments to the approval of new drugs including limited resources and the strict formatting requirements for ADEC submissions. The report concluded that the process that manufacturers had to follow in order for new pharmaceutical products to be approved was overly slow and cumbersome.⁵¹ But also—perhaps more significantly—ANCA recommended that pharmaceuticals approved by British or American authorities should be accepted by Australia without local trials. While activists generally supported ANCA's findings, it was on this point that the report was widely criticised by medical researchers and health department officials. The proposal was seen as a breach of Australia's sovereignty in this area, a threat to the nation's capacity to govern its health system in the context of an international pharmaceutical market. Many also felt that it was a potentially high-risk venture, as Australia had no control over the regulations applied by other countries.⁵² Largely on this basis, Minister Howe did not accept ANCA's findings.

Frustrated by Howe's lack of action on the report, ACT UP announced what they called their 'D-Day' Campaign. D-Day centred on an ultimatum delivered to Howe to increase funding for drug trials and ease restrictions on pharmaceutical

49 Carr, Adam 1992, 'What is AIDS?', in Eric Timewell, Victor Minichiello and David Plummer (eds), *AIDS in Australia*, Prentice Hall, Sydney; Sendziuk, 2003.

50 In the United States, before HIV/AIDS campaigns were successful in changing regulations, it took on average 12 years to gain FDA approval for new drugs and cost the sponsor about US\$231 million. Young, James Harvey 1995, 'AIDS and the FDA', in Caroline Hannaway, Victoria Harden and John Parascandola (eds), *AIDS and the Public Debate*, ISO Press, Amsterdam.

51 Carr, 1992.

52 Prue Power, Interview with the author, 25 May 2004.

approvals before a set date—the allotted D-Day: 6 June 1991.⁵³ There was a long lead-up to D-Day in which ACT UP built its campaign. But when the day arrived, the Federal Government had not responded to the demands. The threatened series of D-Day actions took place, including paint-bombing the offices of Brian Howe and uprooting a prominent floral clock in Melbourne, replacing it with a miniature graveyard of wooden crosses.⁵⁴ Also—in perhaps the most dramatic and well-remembered ACT UP protest—activists in Canberra abseiled from the public gallery into the main House of Representatives in Federal Parliament House while Brian Howe was speaking during Question Time. They threw red streamers (to symbolise red tape) and blew whistles. As activists were thrown out of Parliament House by security guards, they lit orange flares and staged a ‘die-in’ on the front concourse. On the same day, the Sydney chapter of ACT UP mailed a letter to every Member of Parliament containing a single obituary of a person who had died from AIDS in 1991, together with a note stating, ‘This name is for you’.⁵⁵ A statement from ACT UP prepared for the media on D-Day read:

The most important way for people with HIV/AIDS to get access to new treatments is through drug trials. There are not enough trials of new drugs occurring in Australia. This has been acknowledged everywhere, including [by] Minister Howe. Yet his only response to this situation, which has been glaringly obvious for over three years, is to appoint yet another committee...The medical profession chooses to see drug trials as pure medical research to evaluate the efficacy of new pharmaceuticals. However, when there are no other pharmaceuticals available, and when the pharmaceuticals being trialed have already proven to be of benefit, this view is immoral. The drug trialing system must be viewed as a means of giving access to treatments and as such it must ensure that is [sic] accessible and equitable to all people with HIV/AIDS.⁵⁶

ACT UP’s D-Day media briefing also made the point that the beginning of trials for another new drug, DDI, had been delayed by seven months and that the DDI trial protocols meant it was not as widely available as activists believed was ethically warranted. The media kit argued that the Government needed to account for the fact that a small population made Australia a relatively

53 Carr, Adam 1991, ‘Once More Unto the Breach’, *Outrage*, June, pp. 42–4.

54 Woolcock, 1999.

55 Brown, 1991; Anonymous 1991, ‘Diary of a D-Day Full of Daredevil Drama’, *Melbourne Star Observer*, 14 June, p. 3; McDougall, Michael 1991, ‘D-Day Attack Sydney’, *Sydney Star Observer*, 14 June, pp. 1 and 9.

56 AIDS Coalition to Unleash Power (ACT UP) 1991, Cut the Red Tape, Media briefing, ACT UP Demonstration, Sydney.

insignificant market for large pharmaceutical companies, and, as such, there needed to be incentives for companies to submit their products to the Australian approval process.

[One] of the strong points about ACT UP is the amount of research which goes into each issue before there is any action taken. So there's a real responsible approach taken in terms of gaining all of the information first. And I think that's been ACT UP's strength everywhere in the world; in that it's easy to dismiss someone who is out there waving a placard as a ratbag, however, when they can sit around a table with a pharmaceutical company executive and argue trials, it becomes much more difficult to dismiss them as a lunatic or a fanatic. And that's been our top strength, that we can come right in off the street and meet with the Deputy Prime Minister or the Therapeutic Goods Administration and they know that they are dealing with some very substantial activists there who are just as capable of negotiation and argument around the meeting table as they are at doing staged public protests for the media and the general populace.

— Bruce Brown (1991)

Although their response was less radical than ACT UP's, other AIDS activists were also frustrated by the outcome of the ANCA report and continued to lobby on the issue. When Howe announced the formation of a new committee to begin another review, activists were cynical but also pleased to accept invitations to participate. The second review was headed by Peter Baume, a professor of community medicine at the University of New South Wales and former (Liberal) Federal Health Minister. Its findings were released in July 1991.⁵⁷

Baume's review rejected ANCA's proposal to endorse drugs on the basis of overseas approvals, but recommended significant expansion of clinical trials to facilitate much greater access to experimental drugs. Baume also proposed setting in place a strict, and limited, time frame for approvals to which the TGA would be compelled to adhere. Shortly after the report was released, Minister Howe announced that he would implement all of Baume's recommendations. Both activists and many members of the medical profession welcomed Baume's approach to the problem.⁵⁸

57 Altman, Dennis 1992, 'The Most Political of Diseases', in Eric Timewell, Victor Minichiello and David Plummer (eds), *AIDS in Australia*, Prentice Hall, Sydney.

58 Goddard, Martyn 1991, 'Howe Moves on Drugs', *Melbourne Star Observer*, 12 July, p. 1.

Mainly what [the Baume Review] helped with was the reform of the clinical trials system in Australia. Prior to that you had to submit this enormous amount of ridiculous documentation to the TGA which held up the start of the trial for many, many months. What Baume suggested was a new system where if an ethics committee approves the trial, the TGA allows it to go ahead as a notification. And this really speeded up the process. Australia at the time in the late '80s really wasn't on the map in terms of participation in clinical trials in any therapeutic area because, you know, Australia is only 1 per cent of the world pharmaceutical market and companies didn't see it as cost effective—it took a lot of money. That speeding up of the process and a good medical system and committed doctors and patients to do studies in a cost effective way meant that industry became a lot more interested and to this day they remain so. Trials are done in Australia even though we are still only 1 per cent of the pharmaceutical market. That system is still in place and that was brought about because of HIV/AIDS and I think it has worked through, to a certain extent, to other therapeutic areas into cancer and rheumatoid arthritis and Crohn's disease, where the issue is really [about] expensive drugs and how do you get access to them. I don't think those patient groups are as well organised as gay men but they certainly have taken lessons.

— Anonymous (2005)*

* This quotation is an extract from an interview conducted by the author in 2005 with a medical practitioner who worked in the AIDS sector during the 1980s and 1990s.

The fact that the Baume Review happened at all—together with the changes that it led to—is regularly cited (by activists as well as by many people working in government and medicine at the time) as one of the greatest achievements of the AIDS movement. Without agitation by AIDS activists, there would have been no reason for the Government to initiate any changes to the TGA system. Indeed, the issues that Baume considered were certainly not ones that medical professionals or bureaucrats were campaigning on. In many cases, people in these groups actively opposed change.

[Activists] influenced the report and the implementation of it...[There] were issues about Australia still having sovereign rights to test and approve its own medications rather than taking it straight from America. It was obvious that it would have been too controversial to change that. But the way around it was to allow trials, many trials, so that the drugs can come in anyway. It was really quite an interesting way through. So that all the groups, those that wanted to maintain sovereign right, those that wanted access...there were some issues around access still, it didn't please everybody. But on the whole, it was [a] good way around.

— Prue Power (2004)

Activists felt that their concerns had been taken into consideration within the Baume Review and cautiously welcomed its findings. In a public address, the President of AFAO at the time, Bill Whittaker, stated:

It's a major restructure of the drug regulatory system. It's major surgery if you like, on a system that is long overdue for such action. I'm very proud that almost all of the points brought forward to Professor Baume by AFAO on behalf of our constituents were taken up and I think the reasons for this is [sic] two fold—firstly they were very sound and sensible and secondly we had enormous support right around the country from AIDS councils, the PLWA groups, from ACT UP and from doctors and from nurses and many other concerned people in keeping this issue on treatments before the public over the past 18 months. So I think Baume's report is a culmination of the delivery of a very good result. As a result of a lot of hard work that we put into it.⁵⁹

Similarly, Tony Kennan, the then President of the VAC, reported:

The release of the Baume report on the future of drug evaluation in Australia saw the efforts of a long and hard campaign come to fruition. Whilst there are still some concerns about the implementation of the recommendations, the report signals a significant victory for people living with AIDS/HIV.⁶⁰

The Baume Review reflected the success of the AIDS movement in influencing government regulation of pharmaceuticals. This was significant because it was the first time lay-people had held such influence over a major institution within the medical system. AIDS activists also, however, gained authority within the health system at lower levels. The organised dissemination of information about HIV treatments by AIDS activists meant that people with HIV/AIDS were a highly informed patient population, who were able to challenge the advice of their doctors on the basis of their own medical knowledge. Activists had also begun to challenge the authority of doctors and medical researchers who were running clinical trials. This was a powerful position for health consumers to be in, which was carried on in future years as people living with HIV/AIDS established their presence within the HIV sector.

59 Whittaker, Bill 1991, Transcript of a Public Meeting, 16 August, Victorian AIDS Council, Melbourne.

60 Keenan, Tony 1992, 'President's Report', *Annual Report*, Victorian AIDS Council, Melbourne.

[There] had been 11 reviews of the TGA and ADEC processes of varying degrees and none of them had produced anything useful in the way of reforming the drug approval and clinical trial processes. And what generated this was the fact that new treatments were coming along and Australia wasn't going to get to trial them or it would be years until they were put on the PBS and people would die. So you can understand it was pretty easy to ferment a lot of heat in the media and everywhere else around that issue...I think we created the heat, but we had a very sophisticated and well-developed set of arguments to put to the bureaucrats and to the ministers. And we were able to propose a way forward, which led to the Baume report and we were part of that review.

— Bill Whittaker (2004)

There were many sections of the department that were absolutely with us but...[not] the TGA and those old medical bureaucrats who'd been there for decades and who had created all this mythology about how unique and wonderful the Australian system is. And the Australian public I think were led to believe that every time there was an application for a new drug in the Health Department there would be lab tests and Bunsen burners and rats would be tested and of course it was all nonsense, all they really did was review data from well conducted clinical trials. All that sort of mythology, it was immense opposition and the lines were coming from people in the department: 'Oh we will release all these unsafe drugs too early and people will die', and all this sort of stuff. So that's where the opposition was coming from. I think there was tremendous support from politicians of all persuasions, backbenchers... 'cause we lobbied them all. To overcome 12 years, 12 reviews and 20 years of attempts required a sophisticated effort, but it was the emotion, the passion, the concern and the hype—if you want—you could generate around an epidemic where people were dying that cracked the nut. Then it was getting the right people to work around it, and some of those people were community people, [who took] it forward and having a minister who was committed to it, a very brave minister. I think Brian Howe is one of the unsung heroes; we always talk about Blewett, who needs great credit, and his advisors. But Howe delivered a whole set of other stuff, which was continuing a strong strategy and reforming clinical trials and drug approval processes and that flowed on to things...like consumer reps on ADEC.

— Bill Whittaker (2004)

The Expertise of Experience: People living with AIDS

In the late 1980s people living with HIV began to organise separately from the broader AIDS movement, and a national organisation, the National People Living With AIDS Coalition (commonly referred to by its catchy acronym, NPLWAC, pronounced ‘nipple-wack’), was formed in 1988, later to be renamed the National Association of People With AIDS (NAPWA). The first meeting of NPLWAC was held in November 1988 and many State-based coalitions emerged from this. The aim of People Living With AIDS (PLWA) organisations was to construct a visible presence for people with HIV both within the HIV sector and among the broader public.⁶¹ PLWA activists became central to ‘treatment action’ because, apart from the fact that they clearly had the greatest personal stake in the outcomes of any clinical research, they were able to claim ‘expertise’ about HIV/AIDS on the basis of their personal experience of living with the virus.

Coming out

A visit by American activist Michael Callen was one of the inspirations for NPLWAC and other PLWA organisations. Callen had been instrumental in the formation of a movement of ‘self-empowerment’ among people living with HIV in the United States and advocated, as a political strategy, HIV-positive people ‘coming out’ and publicly declaring their HIV status.⁶² At the end of the Third National Conference on AIDS, held in Hobart during August 1988, where Michael Callen had been speaking, people with AIDS were asked to take the stage.⁶³ As PLWA activist Ross Duffin recalls:

It is interesting to look at the positioning of people with HIV and AIDS [at the National AIDS conferences]. At the first two national conferences there were very few, if any, visible people with HIV and AIDS. At Hobart people with AIDS were visible by badges which said, ‘Talk with us—not about us’. Four years ago being that visible was a very brave

61 Menadue, David 2003a, Opening Plenary Session Address, The Art of Living: Ninth Biennial Conference of the National Association of People Living With AIDS, 27–28 October, Cairns, Qld; Woolcock, 1999; McQuarrie, Vanessa 1993, “‘Keep on Acting’ Says Richardson”, *Sydney Star Observer*, 12 November, p. 7.

62 Ariss, 1997.

63 Duffin, Ross 1993, ‘People with HIV and the National Conference’, *The National AIDS Bulletin*, December–January, pp. 20–3; McCallum, Lou 2003, *Review of Paper by Neal Blewett*, Australian Health Policy Institute Commissioned Paper Series 7, University of Sydney, NSW, viewed 5 May 2006, <<http://www.ahpi.health.usyd.edu.au/pdfs/colloquia2003/AIDSpaper.pdf>>

act. People with HIV and AIDS were asked to take the stage and I think this was a real watershed in terms of visibility of people with HIV and AIDS in the AIDS movement.⁶⁴

In the United States, the ‘empowerment movement’ for people with AIDS established a set of principles to guide their activism: the ‘Denver Principles’. The Denver Principles were founded around the goal of increasing the public visibility of people with AIDS. They also sought to challenge the portrayal of people with AIDS as ‘victims’ or ‘sufferers’ of AIDS—terms commonly used in media discourse at the time. It was felt that these terms positioned people with AIDS as subservient and passive in their relationship with the medical profession, the Government and people who cared for them.⁶⁵

Australian PWA organisations followed similar principles and part of their early work involved efforts to reconstruct public perceptions of people with AIDS—recasting negative stereotypes and also encouraging the media to use the term ‘people *living* with AIDS’ rather than ‘victims’, ‘sufferers’ or ‘people *dying* from AIDS’. During the late 1980s, State-based PWA groups and NPLWAC obtained many media opportunities through which they could pursue their objectives. One example of this included a spread in the *Sydney Morning Herald*’s weekend magazine, *Good Weekend*, on 26 November 1988. The article told the stories of several people with AIDS who were trying alternatives to ‘synthetic drugs’. The author emphasised the way in which these men had adopted an inquiring approach to their health care, experimenting with alternative therapies and questioning conventional medical advice. The article managed to present an image of people with AIDS as empowered, and capable of making informed, intelligent decisions about their health.⁶⁶

NPLWAC/NAPWA also sought to influence the nature of medical and social research being conducted around HIV/AIDS. For example, in the mid-1990s they began to agitate for more research that looked at the everyday experiences of people living with HIV/AIDS, resulting in an innovative idea for a study that came to be known as the ‘HIV Futures’ study. Beginning in 1997, the Futures study looked at the health, lifestyle, safe-sex practices, utilisation of services and treatment uptake of people living with HIV/AIDS. The survey has been repeated at regular intervals since this time and has come to be an important source of information about people living with HIV/AIDS that is used regularly by HIV-advocacy organisations and policy makers as well as within government.⁶⁷

64 Ibid.

65 Ariss, 1997.

66 Ibid.

67 HIV Futures is run by the Australian Research Centre in Sex, Health and Society at La Trobe University. Hurley, Michael 2003, *Boundaries and Borders: Researchers and Researched in NAPWA*, Presentation to The Art of Living: Ninth Biennial Conference of the National Association of People Living With AIDS, 27–28 October, Cairns, Qld.

In terms of clinical studies of new HIV treatments, people living with AIDS clearly had a very personal stake (indeed a 'life or death' stake) in the development of effective antiviral medications.⁶⁸ For this reason, many people with HIV/AIDS were willing to participate as research subjects in the clinical trials of any new therapies. The fact that there were a large number of people involved in HIV clinical trials who were also part of an organised social movement meant, however, that the way in which those trials were conducted became a subject of movement attention. PLWA organisations became organised advocacy bodies for people involved in HIV trials. These organisations lobbied for increased involvement of people with HIV/AIDS in the design and implementation of clinical research. The position of NPLWAC/NAPWA on this is articulated well in the following quotation taken from a presentation by the former convener (health and treatments portfolio) of NAPWA, Peter Canavan:

Sometimes, just being present as a positive person can in itself function as a reminder that research deals with flesh-and-blood people, who live daily with the reality that is HIV. We know about lipodystrophy not necessarily because we understand how or why it develops—but because we are the ones who have stood in front of the mirror, and observed the changes over time to the bodies in which we live. When a piece of research involves a high number of hospital visits, or that we are hooked up to an intravenous drug delivery machine, we are the ones who know what that means and what that will feel like, or how various treatments might affect your capacity to work or play or have sex or generally get on with the business of life. It's not that doctors and clinicians aren't aware of it or haven't thought of it: mostly, they are really sensitive towards this stuff, especially in HIV—which in itself is a testament to the power of a partnership between community and researchers for which we have fought and struggled. But the research process involves people whose perspectives and priorities are not always coincidental with our own, at least in the practical sense. I am not suggesting here that anyone wants to do bad or harmful research. But all research disciplines—whether social or clinical science—require people to conform to certain principles about research design, or 'how things get done', or indeed, to answer to particular political, academic or cultural agendas, and these may not always sit comfortably with how HIV positive people see their lives.⁶⁹

68 In 1996, Highly Active Anti-Retroviral Therapy (HAART) was introduced. HAART involves the use of several antiviral medications in combination. The rate of mortality and morbidity associated with AIDS dropped dramatically with the introduction of HAART. Stewart, Graeme 1998, 'You've Gotta Have HAART', *Medical Journal of Australia*, 169, pp. 456–7.

69 Canavan, Peter 2003, Reflecting on 'Our' Involvement in NAPWA, Presentation to The Art of Living: Ninth Biennial Conference of the National Association of People Living With AIDS, 27–28 October, Cairns, Qld.

The relatively small number of HIV-positive people in Australia meant that there was only a small pool of possible research participants for any HIV drug trial. If patients were unhappy with trial protocols, they could elect not to participate or withdraw from the study, and there were not necessarily other people to replace them. Hence, negotiating with activists meant medical researchers had continued access to HIV-positive people who were willing to participate in research. This placed activists in a strong position to negotiate with medical researchers and doctors.

One major issue that brought activists into contest with the medical profession was the use of placebo pills in randomised control trials (RCTs). There were concerns that the use of placebos in RCTs meant some people enrolled in the trial missed out on potentially life-saving medication.⁷⁰ Many activists insisted that placebos were unjustified in the case of a drug such as AZT, which overseas trials had already demonstrated to be effective.⁷¹ There were several occasions where activists threatened to undermine the validity of some placebo-based trials by having their pills tested to see if they were active or not. Those with active doses would halve theirs in order to share it with people on the placebo pill.⁷² Through actions such as this, or the refusal of large numbers of people with AIDS to participate in a trial, community support became virtually a basic requirement if a trial was to go ahead. Hence, the medical community in Australia was pushed into a position where they had to accept greater community involvement in HIV clinical research. As a result, by the end of the 1990s, both NAPWA and AFAO had representatives on the National Centre in HIV Epidemiology and Clinical Research (NCHECR) Protocol Working Group. They also participated regularly in various NCHECR working groups and advisory committees.⁷³

70 Randomised control trials (RCT) were initially developed in the 1940s to test the effects of various drugs on tuberculosis. In RCTs, patients are randomly assigned either to the trial group, where they receive the medication being tested, or to the control group, where they receive a placebo pill. To control for any possible 'placebo effect', patients do not know to which group they have been assigned (in a double-blind trial, the clinician does not know this either). The idea of clinical trials is to remove uncertainty—including that which might come from human emotion or subjectivity—from the process of testing therapies. RCTs are claimed to remove any 'guesswork' from scientific assessment. They are still considered the 'gold standard' in biomedical research—the most effective method of accurately and objectively assessing the efficacy of a treatment regime. Epstein 1996; Willis, Evan 1989, *Medical Dominance: The Division of Labour in Australian Health Care*, Allen & Unwin, Sydney.

71 ACT UP, 1990b.

72 Professor Peter Baume, Interview with Dr John Ballard, Oral History Project: The Australian Response to AIDS, TRC 2815/1, NLA.

73 Canavan, 2003.

The issue of the ethics of [RCTs] using placebos still pops up occasionally. There is still the basic belief in the science community that RCT is the only standard—gold standard. However, the fact that Australia has such a small community weighs in against this for the medical profession. If a trial is perceived to be unethical by the community they will be unlikely to get enough research participants.

— Ian Rankin (2004)

The position of NAPWA was that the personal experiences and opinions of HIV-positive people were just as relevant to clinical trials involving human subjects as medical or scientific knowledge. ‘Medical dominance’ is sustained by the medical profession’s claim to a greater level of expertise over health issues than other groups or individuals. The fact that there was now a patient population which was organised and articulate about their own basis of knowledge, and which had already achieved a legitimate role in the AIDS sector through their earlier campaigns and their role on NACAIDS, represented a significant challenge to medical autonomy. AIDS activists forced medical authorities to take them seriously by continually presenting their position on the ethics and processes of clinical trials. They also threatened to take organised action to undermine the trials.

Contest and Collaboration: Boundaries between medicine and activism

At the 2003 NAPWA Conference, reflecting on relations between the community and medical researchers, Professor John Kaldor stated:

Back in the late 1980s when it was clear AZT was not going to work on its own, there was a sense of urgency. Research had to deliver in a way that I think is hard to comprehend in today’s environment...It was also, as some will remember, a very confrontational environment in many respects...there were hurried and agitated meetings with ACT UP representatives, and there was always someone getting up at every meeting asking: ‘Why not now?’...So it is a sign of incredible progress to be in this situation in Australia. The relationship between researchers and community in Australia is I think, amazingly healthy.⁷⁴

⁷⁴ Kaldor, John 2003, Personal Reflections, Presentation to The Art of Living: Ninth Biennial Conference of the National Association of People Living With AIDS, 27–28 October, Cairns, Qld. Professor John Kaldor, PhD, is Deputy Director and Professor of Epidemiology of the National Centre in HIV Epidemiology and Clinical

The ‘treatment action’ campaigning of the AIDS movement pushed activists and the medical profession towards working more closely together in an increasing number of forums. AIDS activists, particularly representatives from PLWHA organisations, established a regular presence in all aspects of HIV health delivery including prevention and health promotion through to working with pharmaceutical companies.⁷⁵ It is now common practice for community representatives (lay-people) to be consulted about the ethics and processes of clinical trials, and community-based AIDS organisations are routinely represented on the working committees of research organisations such as the NCHECR. The TGA’s ADEC also now has a community representative and community consultation has also been extended to other disease groups—a shift in medical practice that is often attributed to the work of the AIDS movement.⁷⁶

Although this style of community participation in health has become increasingly commonplace and easy to negotiate, when they were first being established in relation to HIV/AIDS there was a significant amount of tension coming from both activists and doctors. As Peter Canavan recalls: ‘At first these [partnerships] were tentative and nervous. There was some mutual suspicion, and a sense of being off “familiar” turf.’⁷⁷ An alliance of this type between doctors and activists had no historical precedent and although their relationship was ostensibly ‘professional’, trust still needed to be established. A number of doctors in the field had to confront their own personal prejudices. The medical profession is historically quite conservative, and, in the early 1980s, many medical doctors had never known any gay men and had only ever formed opinions about them within the context of negative stereotypes and assumptions about homosexuality.

According to one medical practitioner working in the AIDS sector at the time:

I think more of the tension was within the health system itself where the sort of reaction against HIV/AIDS was well: ‘Infectious disease, gay men, don’t like gay men’—particularly among conservative surgeons, it was: ‘Why should we be treating them, we might be getting this infection by treating them, so why should we treat them?’⁷⁸

Research. He has been responsible for coordinating national surveillance for HIV/AIDS since 1989. He has also worked on a range of epidemiological research programs in blood-borne viruses and sexually transmissible diseases.

75 Canavan, Peter 2004, ‘Because It’s Personal: What Good Advocacy Can Achieve, and How’, *The Australian Health Consumer*, (1) (2003–04), pp. 17–20.

76 Bill Whittaker, Interview with the author, 5 November 2004.

77 Canavan, 2004.

78 This quotation is an extract from an interview conducted by the author in 2005 with a medical practitioner who worked in the AIDS sector during the 1980s and 1990s.

When AIDS emerged, these doctors were suddenly expected to not only acknowledge and accept gay men as patients, but to form professional alliances with openly gay activists. One medical doctor described the tensions, stating:

In the medical system we've never had [the orthodox medical system has never had] contact with gay men in the way that the AIDS epidemic brought out because most gay men at the time were cared for, for their STDs, by either the public STD clinics or the private general clinics that specialised in STDs. They were generally run by gay men and obviously gay men felt comfortable going there because they were non-judgmental, because homosexuality wasn't really out of the closet in the late '70s, early '80s. So I think the medical system never really experienced gay men and it was pretty confronting—confronting for all of us. I think for someone like Penington, or Gordon Archer, it was particularly confronting for them, being older straight men, probably grew up in an era when homosexuality was not a good thing in terms of their societal norms...But having said that I think they respected the dialogue because it was obviously coming from men who were well educated and knew the issues. But it was certainly tense for a while.⁷⁹

As the above quotation suggests, one of the means by which the social divide was bridged between activists and doctors was the capacity of activists to engage in medical discussion. Activists had worked hard to become literate in medical jargon and could comprehend the biological processes related to HIV/AIDS and HIV treatments. To some extent this undermined the power of the medical profession to control debates about HIV/AIDS. The 'mystical' and elite status of medical knowledge was destabilised. But perhaps more importantly, activists' self-education won them much respect among medical professionals, loosening some of the boundaries between 'doctors' and 'lay-people'.

The combination of media portrayals of 'AIDS victims' together with a paternalistic and highly technological medical system were powerful forces against seeing people with AIDS as active agents in control of their lives. The battle fought by people living with AIDS has revolutionised the relationship between the medical system and a group of erstwhile 'patients'.

— Victorian AIDS Council (1993)*

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

On this basis, the AIDS movement ushered into the Australian health system a new set of expectations about the role of non-medical people, and patients, in health issues. The medical profession was forced to confront their reluctance to engage professionally with lay-people. As one medical doctor stated:

It would have been fair to say that we were a little bit imperious about the whole thing, you know, patients shouldn't be interfering in what doctors do. I think that was a fairly common attitude at the time because we had never confronted that. We felt that we were delivering effective health care in the medical system and patients didn't generally query too much our recommendations. And when patient advocacy groups start to do that, it is a bit threatening to a lot of doctors. But we got over it and now they're engaged and extremely helpful in many of the things we do—particularly about whether trials will be acceptable to certain patient populations.⁸⁰

[Community activists and the medical community] worked hugely closely together—often behind the scenes. Often one telling the other what was going on so that, say, ACT UP could be at the right place at the right time to interfere with discussions with a drug company who was saying, you know: 'We'll do this but...we won't make it available to the people who are really sick.' And so their talks would get interfered with because the people...the medical fraternity would make sure the community sector knew what was going on so they could be there. Other examples [were] making sure the community sector were involved in things like drug trial planning, importation of drugs, lobbying for expanded access, increased number of people being able to prescribe [more GPs] and working together to get that information out.

— Levinia Crooks (2005)

Boundary Crossers

Conversely, while the medical profession was forced to accept the involvement of activists in their work, activists had to learn to work productively within the medical system and institutions to which they had demanded entry. This was facilitated by mutual goals between some sections of the medical profession and activists. For instance, general practitioners supported AIDS activists to lobby for faster approval of AZT. As long as AZT prescriptions were available only within a clinical trial, GPs were limited in the treatment options they could offer

⁸⁰ Ibid.

and locked out of the loop in terms of HIV treatment. So, in part for their own interests, GPs often lobbied in support of activists.⁸¹ Also, doctors and activists came to rely on support from each other to attract funding into the HIV sector.

Health social movements have been referred to as 'boundary crossers'.⁸² While health activists generally engage in protest activities such as street demonstrations and lobbying, they also often partake in formal collaboration with scientific and research institutions. This blurs the traditional boundaries between 'medicine' and 'lay-people'. But by working with medical institutions, health social movements also move beyond commonly agreed definitions of social-movement activity, collaborating with the 'opposition' and adopting an 'expert' identity of their own. This distinctive characteristic of health social movements occurs in part because activists are dependent on science. There are few, if any, other social-movement 'issues' where individual movement actors are dependent on the 'targets' of their political action (their political opponents) for treatment or even survival. For this reason, health social movements generate a culture of action that is not simply focused on sparring with opposing forces. Building collaborative relationships is part of their political strategy. Collaboration between activists and doctors is, in this sense, a radical manoeuvre.⁸³

The increasing alliance between AIDS activists and the medical profession that developed through the 1980s and 1990s is testament to the way in which AIDS activists challenged the dominance of the medical profession, not only through political contest, but through finding ways for lay-people to participate in the health system. The professional boundaries of the medical establishment were impinged upon by activists not only through overt political contest, but through their cooperative participation in the health system.

Boundaries were also crossed, however, by the number of gay doctors who became involved in the HIV/AIDS sector. Not surprisingly, the massive impact HIV/AIDS had on the Australian gay community was of personal interest to gay men with medical training. These doctors became active participants in both HIV/AIDS medical treatment and community activism.⁸⁴

81 Ariss, 1997.

82 Brown, Phil, Zavaestoski, Stephen, McCormick, Sabrina, Mayer, Brian, Morello-Frosch, Rachel and Gasior, Rebecca 2004, 'Embodied Health Movements: New Approaches to Social Movements in Health', *Sociology of Health and Illness*, 26(1), pp. 50–80.

83 Ibid.

84 David Lowe, Interview with the author, 12 July 2005.

To capture an accurate picture of it you have to capture the complexity of it and the fact that there were people on both sides of the fence who wore two hats... There was a tension between powerful medical academics and grassroots medical people who [had] greater insights into the grassroots practicality... [There] was greater interest in the power and politics from the others. That was the sort of tension. So you'd often see this dichotomy referred to between people like David Penington, representing medical academics with no real reason to be involved apart from the fact that they considered themselves to be important, [and] the more grassroots medical people, many of whom were gay, who had lots of good reasons to be involved and were much closer to what was going on in a practical sense. To me, that was a big tension.

— David Plummer (2004)

The boundaries of any profession are determined by who is allowed 'in' and who is not. Once people are 'in'—a legitimate member of the profession—they are expected to adhere to a particular set of cultural and moral norms. Steven Shapin discusses this point with reference to what he terms the 'thought collective' of medicine.⁸⁵ The thought collective is a 'fund of knowledge' from which individuals draw and to which they contribute. Ideas and information are shared and new knowledge is formed as part of a group process of dialogue and discussion. To remain part of the thought collective, members must adhere to its conventions.⁸⁶

The culture of the medical 'thought collective' is to a large extent sustained by the standardised training process through which all doctors must pass. Doctors are, in a sense, trained in the cultural norms of the medical profession. But beyond this, there are bonds of trust within the group. Doctors trust that other members of the collective operate within a similar framework of knowledge and cultural norms to their own, and that the knowledge contributed to the thought collective is legitimate in terms of the expectations of the medical profession. As Shapin describes, 'in order for that knowledge to be effectively accessible to an individual—for an individual to have it—there needs to be some kind of moral bond between the individual and other members of the community'.⁸⁷

Gay doctors sat within two groups: the medical profession and the gay community. In effect, they had access to the *moral bonds* of both collectives, thus providing a bridge between the AIDS movement and the medical world. Gay doctors effectively gave the AIDS movement a cultural 'in' to the medical establishment and provided a more legitimate basis from which activists could contribute to

85 Shapin, Steven 1994, *A Social History of Truth*, University of Chicago Press, London.

86 Ibid.

87 Ibid.

medical knowledge. As well as being a source of medical information for the gay community, 'gay doctors' contributed to the capacity of the AIDS movement to speak 'credibly' on AIDS in medical circles. For this reason, 'gay doctors' played an immensely important role in establishing relations of trust between the medical profession and AIDS activists.

[Amongst] heterosexual scientists and doctors who then needed to become involved there was of course understandably a little uncertainty dealing with this new group. It's not a paradigm that they had worked with either dealing with the community, not to mention gay men. In any case the 'doctor knows best' mentality is very, very strong. And a lot of them were fairly shocked by having a verdict challenged or being forced to work with activists. So...there were tensions at times. But again trust was built up fairly quickly...because [of] money, community activism was delivering money for doctors, community services and hospitals...they are not good at that sort of lobbying, we did that sort of lobbying, we did that for them. We were lobbying government with them but generally more effectively to enable research and services to happen. So I think that partnership is really one of the strongest aspects of the Australian response and that continues.

— Bill Whittaker (2004)

Mistrust and Medical Activism

The development of trust between AIDS activists and the medical profession marked an interesting progression in the social history of gay men in Australia. The history of homosexuality meant that gay men were less likely to trust medical science than many other social groups might have been. Gay men were reluctant to leave decisions about treatment of a disease that affected them so intimately in the hands of scientists, even when potential 'miracle drugs' were on the scientific horizon. Mistrust of scientific interests also rested on a legitimate fear of discrimination. As has been described in previous chapters, the medical establishment had historically been involved in attempts to 'cure' homosexuality through barbaric practices such as electroshock therapy. Whether or not this history came directly to the minds of AIDS activists, it certainly meant that there was no prior relationship of trust between the gay community and (heterosexual) doctors. When AIDS hit, gay men doubted the confidentiality of medical practices and were therefore wary of clinical interventions such as HIV testing. There was also a general concern that the objectives of scientific research often overrode the personal interests and needs of gay men.⁸⁸

88 Misztal, Barbara 1996, *Trust in Modern Societies*, Polity Press, Cambridge; Kimsma, Gerrit 1990, 'Frames of Reference and the Growth of Medical Knowledge: L. Fleck and M. Foucault', in Henk Ten Have, Gerrit

AIDS activists' mistrust of doctors and of science was highly important in determining the course of the AIDS movement.⁸⁹ Two key strategies adopted by the AIDS movement throughout its treatment-action campaigns were: 1) to assert an alternative basis of expertise, grounded in personal experience and community need, which challenged the autonomy of medical intervention; and 2) to ensure activists gained enough technical knowledge about the physiology of AIDS and the processes of clinical trials to engage effectively in medical dialogue. AIDS activists ensured that they fully comprehended the scientific aspects of HIV/AIDS and the processes of the medical system because they did not trust it to act in their interests otherwise.

What is interesting about the AIDS movement, however, is that over time relations of trust—or at least working relations that involved some level of trust—were established between the AIDS activists in the gay community and medical doctors and researchers working in the area of AIDS. This was not uncontested trust, or what could be termed 'blind faith' in medical institutions on behalf of activists. Rather trust was built on the basis of a negotiated relationship. What the AIDS movement achieved was a renegotiation of the trust relationship between lay-people and the medical profession.

Kimsma and Stuart Spicker (eds), *The Growth of Medical Knowledge*, Kluwer Academic Publishers, Dordrecht.

89 It is also worth noting that gay men and lesbians often have the experience of feeling 'outside' mainstream culture. Whether or not this is based on mistrust of the mainstream, it has meant that the gay community has developed its own facilities. In the 1980s, this included a network of gay-friendly GPs. Phil Carswell, Personal communication, 25 October 2006, Melbourne.