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Movement, Knowledge, Emotion: Gay Activists and the
Australian AIDS Movement

A Thesis Submitted for the Degree of Doctor of Philosophy at the
Australian National University

Jennifer Power

April 2007
I declare that authorship of this thesis is entirely my own work. All sources used have been appropriately acknowledged.

Signed: 

Jennifer Power
April 2007
Acknowledgements

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Abstract

This thesis examines community activism around HIV/AIDS in Australia. Specifically, it looks at the role that the gay community played in the social, medical and political response to the virus. Drawing conclusions about the cultural impact of social movements, the thesis argues that AIDS activism contributed to improving social attitudes toward gay men and lesbians. It also concludes that AIDS activism challenged some entrenched cultural patterns of the medical system in Australia, allowing greater scope for non-medical intervention into the domain of health and illness.

The thesis draws on a range of sources, including archival documents and indepth interviews, to create a narrative history of the development of AIDS activism. Drawing from social movement theory, the thesis looks at the structure and form of the ‘AIDS movement’ to explain how it mobilised as it did. The narrative history approach enables the study to detail the rise of the AIDS movement in historical context, exploring it as a product of the history of homosexual discrimination and marginalisation in Australia. The thesis also highlights the role that emotions such as fear, anger and trust/mistrust played in both motivating and framing movement action.

While the thesis is a study of the impact of a social movement, it does not attempt to measure, in a positivistic sense, the tangible outcomes of the AIDS movement. Rather, it looks for shifts in cultural codes or new knowledges that were produced by movement action – what has been termed the ‘hidden efficacy’ of a social movement. This approach draws on the sociology of knowledge, looking at the
way AIDS activists interjected new ‘ways of knowing’ into existing social discourses about homosexuality as well about as public health and medicine.

Part one of the thesis is about the history of homosexuality in Australia and the rise of the AIDS movement. It also details the way in which the AIDS movement was able to influence public attitudes toward gay men and lesbians. Part two of the thesis looks at the way in which the AIDS movement challenged the entrenched authority of western medical professionals in the public health sector by demonstrating an alternative, socially-oriented approach to HIV prevention. AIDS activists introduced an alternative framework of knowledge to the medical arena, emphasising the relevance of ‘non-medical’ knowledge to clinical decision making. Part three of the thesis looks at the way in which AIDS activists confronted the stigma and shame surrounding HIV/AIDS by creating memorials to people who had died from AIDS. These memorials deliberately sought to replace feelings of shame associated with HIV/AIDS by legitimising and paying respect to feelings of grief related to AIDS.

This study shows how social movement action is co-currently emotionally, historically and intellectually derived – in this case a product of the fear, grief and anger associated with AIDS converging with the history and political capacity of gay men in Australia. The thesis concludes that a detailed historical reading of movement action can reveal the areas where movements have challenged conventional cultural, moral or social codes. Social movements contribute to the cultural stories and moral scripts that determine how we perceive the world.
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<td>AAC</td>
<td>AIDS Action Committee</td>
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<td>ACON</td>
<td>AIDS Council of NSW</td>
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<td>ACT UP</td>
<td>AIDS Coalition to Unleash Power</td>
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<td>ADEC</td>
<td>Australian Drug Evaluation Committee</td>
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<td>AFAO</td>
<td>Australian Federation of AIDS Organisations</td>
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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ALSO</td>
<td>Alternative LifeStyles Organisation</td>
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<tr>
<td>ANCA</td>
<td>Australian National Council on AIDS</td>
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<td>ANCAHRD</td>
<td>Australian National Council on AIDS, Hepatitis C and Related Diseases</td>
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<td>ASHM</td>
<td>Australian Society for HIV Medicine</td>
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<td>BGF</td>
<td>Bobby Goldsmith Foundation</td>
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<td>BTS</td>
<td>Blood Transfusion Service</td>
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<td>GMHC</td>
<td>Gay Men’s Health Centre</td>
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<td>GRL</td>
<td>Gay Rights Lobby</td>
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<td>HFA</td>
<td>Haemophilia Foundation of Australia</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>KS</td>
<td>Karposi’s sarcoma</td>
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<td>NACAIDS</td>
<td>National Advisory Committee on AIDS</td>
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<td>NAPWA</td>
<td>National Association of People with AIDS</td>
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<td>NBTS</td>
<td>National Blood Transfusion Service</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>NPLWAC</td>
<td>National People Living with AIDS Coalition</td>
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<td>PCP</td>
<td>Pneumocystis Carinii Pneumonia</td>
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<td>STD</td>
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<td>TGA</td>
<td>Therapeutic Goods Administration</td>
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Introduction
Social Movements, Social Knowledge: AIDS Activism in Australia

Perhaps the most striking feature of the HIV/AIDS epidemic in Australia has been the organised response of affected communities, most notably that of gay men. The Australian gay community and their supporters established the first ‘safe sex’ HIV prevention campaigns, created large volunteer-run care and support networks for people living with HIV/AIDS, produced volumes of information to educate people and inform policy debate, and established a presence at the forefront of public health policy-making regarding HIV/AIDS. This thesis looks at the development of community activism around HIV/AIDS and the role that the gay community played in the overall social, political and medical response to the virus.

There are two central contentions explored in the thesis. The first is that AIDS activism, through developing a strong public presence and media profile for gay activists, contributed to a change in social attitudes toward gay men and lesbians. The second is that AIDS activists, through asserting the right for communities to be involved in the management of public health and clinical research regarding HIV/AIDS, challenged the traditional authority and dominance of the medical profession in Australia. The thesis explores the way in which organised, collective action around HIV/AIDS reconfigured social knowledge about homosexuality and about public health and scientific research.
HIV/AIDS in Australia

Australia was among the first countries in the world to report cases of AIDS. In May 1983 doctors from St Vincent’s Hospital in Sydney announced that the first case of AIDS had been diagnosed the previous November (1982) in a gay man who had been visiting Sydney from New York (Menadue, 2003:19). Hindsight would prove that there were almost certainly many more undiagnosed cases of both HIV and AIDS in the community at this time, but the official identification of that first case was enough to prompt acknowledgement that the mystery ‘killer disease’ from the USA had found its way to Australia.

From this first diagnosis in 1982 until the end of 2005 there were 25,243 reported diagnoses of HIV in Australia (or an estimated 22,360, after adjusting for multiple reports). Of these, 9,759 people had been diagnosed with AIDS and 6,594 AIDS-related deaths had been recorded. When Highly Active Anti-Retroviral Treatment (HAART) became available in Australia in 1996 there was a sharp drop in the number of people with HIV who progressed to AIDS. As such, the rate of AIDS deaths also declined. In 1994, there were 955 reported new cases of AIDS. This figure had dropped to 194 by 2005 (WHO, 2002; NCHECR, 2006:1). Evidence suggests that the virus spread most rapidly through the Australian community in the early years of the 1980s, with the incidence of new HIV diagnoses\(^1\) peaking in 1984 (NCHECR, 2006:1). A ‘second wave’, or significant resurgence of HIV, that in the mid-1980s some people had predicted, has not occurred, although data released in

\(^1\) Measured over a 12 month period.
2003 indicated that rates of new HIV infections were increasing in Australia for the first time in over a decade (AFAO 2003; Wilkinson and Dore, 2000:277).

In Australia, HIV/AIDS has overwhelmingly been a disease that affects men who have sex with men. While the rate of HIV transmission among heterosexuals – particularly those in marginalised groups such as indigenous people – has increased slightly in recent years, the majority of HIV infections (80.5 per cent of all infections between 1982 and 2005) have occurred through male to male sex (NCHECR, 2006:7).

The pattern by which HIV has spread through Australia differs from that seen in other western countries, including France, the USA and Germany. In all these countries HIV has moved much more widely into the heterosexual population and the rate of HIV among intravenous drug users and women is much higher than in Australia. In the USA, for example, heterosexual sex accounted for 33 per cent of all newly-diagnosed HIV cases in 2004, with 47 per cent attributed to men who have sex with men (Wilkinson and Dore, 2000:279; CDC, 2005, CDC, 1985:1). By comparison, in Australia 85.4 per cent of new diagnoses of HIV in 2005 were attributed to male-to-male sex, a similar proportion to earlier years (NCHECR, 2006:3). Furthermore, Australia has maintained a lower per capita rate of reported HIV infections than many OECD countries (Wilkinson and Dore, 2000:279; CDC, 2005: CDC, 1985:1).

The epidemiological pattern of AIDS when it first emerged in the early 1980s led many people to suspect that it was a disease exclusive to gay men. Symptoms of the
disease had first been recognised in the United States among gay men and before the term AIDS was devised, the syndrome was being called Gay Related Immune Deficiency (GRID). It was also referred to as the 'homosexual cancer' or the more derogatory 'gay plague'. Early theories regarding the cause of AIDS pointed to factors such as excessive semen in the blood stream from anal intercourse or the 'fast-paced' lifestyle of many gay men (Seidman, 2002:377). Although it was not long before the first cases of AIDS among heterosexual people began to appear in Australia, the belief that there was an inherent association between AIDS and the lifestyle and sexual choices of gay men and was already strongly entrenched in public consciousness.

**HIV/AIDS and Gay Liberation**

The 1980s and '90s witnessed the rise of consumer-based health movements, both in Australia and across the western world. But when AIDS first appeared in the early 1980s the sophistication and breadth of the organised response to it by the gay community was unheralded. To date in this country, no other community or consumer based health movement has captured the same level of public and political influence as that of the AIDS movement. In part, this was due to the nature of

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2 HIV (Human Immuno-deficiency Virus) is the virus that leads to a breakdown of the immune system causing the collection of illnesses and infections that are known as AIDS (Acquired Immune Deficiency Syndrome). HIV is not the same as AIDS and the acronyms should not be used interchangeably. A person living with HIV is not necessarily a person who has AIDS. An HIV positive diagnosis is different to a diagnosis of AIDS. When I use the term AIDS, rather than HIV/AIDS or HIV, I am referring either to the physiological condition of AIDS or to the time period, before 1985, when HIV had not yet been discovered.

3 While it is common to refer to HIV and AIDS in conjunction with each other, as in HIV/AIDS, to signify the medical and social association between the two, I have chosen to use the terms 'AIDS

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HIV/AIDS itself. The illness entered the public arena as a ‘mystery disease’ for which there was no known cause and no cure. Concerns that the disease would sweep rapidly across the whole population provided it with media and political attention few medical conditions receive. But more significantly, AIDS was a contagion associated with a set of social and sexual practices traditionally shunned by mainstream society: homosexuality, illicit drug use and prostitution. From the beginning, AIDS was perceived to be a disease of deviance, criminal acts and immorality.

It was these associations, emerging alongside large numbers of people becoming ill and many deaths, that prompted gay communities in Australia to mobilise in response to AIDS. There were indications, and fears, that the contagious nature of the illness would provide license for a formal crackdown on recently won social freedoms of gay men, such as the decriminalisation of homosexual acts. As well as threatening lives, AIDS made vulnerable the civil liberties and public acceptance of lesbians and gay men that had slowly been expanding throughout the 1970s. Gay men in Australia took action not only to protect people afflicted with AIDS and draw attention to their needs, but to defend the broader social rights of gay men and lesbians. During the 1980s and early 1990s gay activism became enmeshed with the

activism’ or ‘AIDS Movement’ rather than ‘HIV/AIDS activism’. This is, in part, a stylistic decision. AIDS activism is shorter and more readable. However, it is also indicative of the fact that AIDS activism in Australia emerged before HIV had been diagnosed and named. As such it is historically accurate to refer to early activism as AIDS activism. Further, before the antibody test for HIV became available, the only way of knowing that someone was infected were the physical symptoms of AIDS. Hence much of the stigma around AIDS in the early 1980s was associated with the visible attributes that came to signify AIDS such as Karposi’s sarcoma.
politics of HIV/AIDS. Organisational structures that had been established in previous campaigns for gay and lesbian rights were called into play, and the cultural and political framework of the gay movement was reoriented toward the immediate problem of AIDS. Many hundreds of people became involved with the AIDS movement. Indeed, as long-term Australian gay activist Lex Watson once wrote, the spectre of AIDS mobilised the gay community in a way that previous issues of anti-discrimination and gay law reform never had.

AIDS has fundamentally changed the style, the content and, indeed, the whole notion of gay male politics. And it has done something – unfortunately, as it happens, but nonetheless in a very real way – that nothing else in the gay community did (Watson, 1988:13).

At issue for the AIDS movement was the way in which HIV/AIDS, and the people most affected by it, were constructed in the public’s imagination. It was this that would inform policy and direct the treatment of HIV/AIDS by government and public health authorities. If HIV/AIDS continued to be seen as a disease of ‘blameworthy deviants’, then punitive and restrictive measures to control its spread could be considered justifiable. AIDS activists campaigned on a number of fronts: to reduce stigma and discrimination against gay men, and people with HIV/AIDS; and

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4 This study focuses on the response of gay male activists to HIV/AIDS. While there were a number of lesbians who were involved in AIDS activism, and a study of their role would be worthy of a thesis in its own right, I do not discuss in detail the role of lesbians in Australian AIDS activism.
to ensure that the concerns of the gay community were taken into account when developing public health policies around HIV/AIDS.

Taking a cue from the USA, where activists had already begun mobilising in response to what Phillip Kayal refers to as the American government’s ‘homophobic disinterest’ in AIDS, gay men in Australia began to take action. The gay community was organising around AIDS even before the first Australian case was diagnosed in 1982 (Kayal, 1993:5; Stockdill, 2001:206).

The AIDS Movement

HIV/AIDS brought the gay community under intense public scrutiny. As issues around the nature, legality and social acceptance of homosexuality became increasingly prominent in public discussions around HIV/AIDS, the AIDS movement organised to ensure it had a presence in this. Paradoxically, despite the devastation HIV/AIDS caused the gay community, it brought unprecedented opportunities for AIDS activists to present publicly a perspective on homosexuality that had previously been sidelined by the media and public commentators – a perspective that was affirming of gay identity and refuted the image of gay lifestyles as being deviant or at odds with mainstream society.

Along with campaigning to protect gay and lesbian rights in the wake of HIV/AIDS, activists also began to organise their own response to the virus, educating community members about how to prevent HIV/AIDS and establishing networks to care for...
people who were ill. When the Federal Government began to formulate its response to the virus in the mid-1980s, the AIDS movement campaigned for community activism to be formally incorporated into Australia’s national HIV/AIDS prevention strategy. Activists argued that the Government should provide financial support to community-based organisations to take the lead in HIV prevention. They also demanded that the people most affected by the disease should be consulted on all aspects of HIV/AIDS policy-making. Over time, the strength and consistency of AIDS movement action meant that activists became key players in the formal government and medical responses to HIV/AIDS.

The AIDS movement also helped to enshrine the concept of ‘community participation’ within the Australian public health system. This occurred despite resistance from the some sectors of the medical fraternity who felt that such wide-ranging involvement of the gay community impeded public health efforts by ‘de-medicalising’ AIDS policy. The AIDS movement came into contest with parts of the medical profession over the management of HIV/AIDS in a public health context as well as around issues related more directly to the clinical testing and research of HIV medications. AIDS activists demanded that ‘lay people’ – community groups affected by HIV/AIDS – be given a measure of expert status equal to that of medical professionals in scientific and clinical decision-making regarding HIV/AIDS. They argued that the experience of living with HIV/AIDS was a source of knowledge that needed to be considered when making ethical or scientific decisions about HIV/AIDS research or clinical trials for new HIV medications. Activists backed up their arguments with political strategies that threatened to undermine the feasibility
or validity of clinical trials, such as collectively refusing to participate in studies. In this way, the capacity for medical science to work autonomously from AIDS activists was lessened and the long-held authority that medical professionals had held over patients and laypeople was destabilised. Over time, AIDS activists came to be represented on ethics committees and research working groups in a number of Australian medical research institutions.

This thesis looks at how the AIDS Australian AIDS movement was able to gain enough political strength and public profile to influence the policy response to HIV/AIDS, and to shape public knowledge about the virus and those affected by it. The emphasis of the study is not on the tangible or policy outcomes achieved by the AIDS movement. Rather, I am interested in how the actions of the AIDS movement contributed to changing public knowledge about, and attitudes towards, homosexuality, and how the AIDS movement was able to interject a new perspective into public health. I also highlight the role of emotions such as fear, anger and trust/mistrust in both motivating and framing movement action. I also look at the way in which movement actors consciously sought to reframe the experience of emotions such as shame and grief associated with HIV/AIDS and homosexuality.

Thesis Outline

The thesis is organised both thematically and chronologically. I begin with an analysis of the relationship between gay identity and the development of the AIDS movement as it emerged through debates about HIV antibody testing in the mid-1980s. I then look more closely at debates that occurred in the latter half of the 1980s
and early 1990s around the nature of the medical and public health response to HIV/AIDS. I conclude with a discussion of the AIDS Memorial Quilt, a project that began in the late 1980s and continues into 2007. These three sections are explained in more detail below.

**Theory and Method**

Two dominant theoretical approaches to social movement research, broadly referred to as *Resource Mobilisation Theory* and *New Social Movement Theory*, provide a framework for studying the way in which social movements mobilise and the varying organisational and tactical forms they take. In Chapter One I look at the benefits and limitations of existing social movement theory for this study, arguing that this approach does not provide an adequate framework for studying the cultural changes effected by social movements. I then explore the relationship between the sociology of knowledge and social movement theory and suggest that a meeting of these two approaches provides the most useful theoretical framework for this thesis. Central to this is the notion of social movement ‘frames’ or ‘framing’. A social movement frame is essentially the frame of knowledge or ideological stance of a movement. It is the movement frame that is contested through social movement action – movements compete with other social groups and actors for their framing of reality to be considered the most legitimate or authoritative view. Through movement action new ideas are introduced into the public realm. In this sense, the movement frame becomes the basis for instigating new social or political awareness, or generating cultural change. I argue that the frame of the AIDS movement brought
into public consciousness new knowledge about homosexuality and introduced an alternative perspective on public health and scientific research.

Movements, of course, emerge within a complex historical and social setting – 'what we know' about the world cannot be attributed to any single factor. Therefore, the framework I develop for this study is not one that sets up a positivist assessment of movement outcomes (such as measuring tangible changes in policy or acquisition of resources). Rather, in Chapter Two, I suggest a way of reading movements 'hermeneutically', locating the AIDS movement historically in relation to existing medical discourse and knowledge about homosexuality. The thesis uses a narrative history approach to tell the story of the AIDS movement, developed using a range of data collection techniques including indepth interviews and archival searches.

**HIV and Homosexuality**

The story of the AIDS movement emerges from the history of homosexuality in Australia. Chapter Three begins with a discussion of the social and political status of gay men and lesbians in the decades leading up to the AIDS crisis. My intention is to provide a historically rich account of the emergence of the AIDS movement, contextualising the motivation for movement action and the form that the movement took during this time. This chapter explores the notion that mobilisation of the AIDS movement was a product of gay history, both the history of discrimination and the history of the gay and lesbian liberation movement. The ‘cultural frame’ of the AIDS movement developed through the convergence of this history with the fear and uncertainty gay men experienced when AIDS arrived. I argue that previous
experiences of prejudice and discrimination meant that gay men were less inclined than other social groups may have been to trust authorities to care for their needs or protect their civil rights in relation to HIV/AIDS. There was a great deal of fear that punitive measures to control the actions of gay men would be (re)introduced. For this reason, the gay community mobilised to defend their interests at a political level, and also to take the care and protection of the gay community and people with HIV/AIDS into their own hands.

Chapter Four explains how negative public attitudes toward homosexuality were exposed over the course of the AIDS epidemic. This occurred through a number of high-profile public debates. For example, when it was discovered that AIDS was transmissible through blood products (blood and organ donation) many public figures expressed anxieties that gay men would, either through malice or irresponsibility, begin to spread AIDS to the heterosexual population. There were calls for the introduction of legal measures to restrict the actions and freedoms of gay men. The AIDS movement was, however, in a position to influence the course of debates such as this. They presented to the public an image of gay men that was informed, intelligent and responsible. For the first time, gay activists had opportunities to appear regularly in the media to refute long-held, stereotypical images of gay men as deviant and anti-social or hedonistic and irresponsible. Ironically, the emergence of a disease that threatened further entrenchment of prejudice against gay men and lesbians also created an opportunity for activists to reframe public perceptions about homosexuality.
Contesting Medical Knowledge

Chapter Five looks at the contribution made by the AIDS Movement to public health policy regarding HIV/AIDS. AIDS activists viewed the virus through the lens of their experiences as gay men. They saw the social justice and human rights issues related to HIV/AIDS as primary concerns and argued that communities needed to be at the forefront of education and prevention efforts. Its social orientation brought the AIDS movement into conflict with proponents of a more traditional, medically-oriented approach to public health – one generally based on wide-scale clinical testing, quarantine and vaccine research. AIDS activists were mistrusted by many within the medical profession, accused of lacking concern for scientific evidence in order to promote what was perceived to be their selfish agenda. Nevertheless, the ‘community participation’ approach to HIV prevention demonstrated by the AIDS movement continued to win support from the Federal Government and this new model of public health came to be considered legitimate and effective.

Chapter Six looks at the relationship between the AIDS movement and the medical profession through an analysis of controversies surrounding the introduction of new HIV anti-viral medications in the latter half of the 1980s. When the first anti-retroviral treatments became available in the USA, the AIDS movement began to campaign for changes to Australian regulations around pharmaceutical approval. Activists demanded faster access to medications that were already available overseas, claiming that existing processes of clinical testing were inefficient and unethical because they denied access to potentially life-saving medications. By raising questions about the ethics and processes of pharmaceutical trials, the AIDS
movement challenged the autonomy of medical expertise in this area. Activists claimed an alterative basis of expertise, demanding that the personal experience of living with HIV/AIDS be considered a credible form of knowledge, on par with medical knowledge, in relation to clinical decisions. In effect, activists challenged the right of medical doctors to have control over HIV/AIDS, not only in the public health arena, but also with regards to medical treatment and clinical research. While this challenge to medical authority generated tension between activists and some members of the medical profession, over time a more trusting relationship developed between the two groups. Activists came to be included in a number of research working groups and clinical research ethics committees.

**Emotion and Identity**

Chapter Seven further explores the relationship between the AIDS movement and the production of knowledge about both homosexuality and people with AIDS through a discussion of AIDS memorials. The AIDS Memorial Quilt and the annual Candlelight Vigils were created as memorials for people who had died from AIDS-related illnesses. From their inception, both the Quilt and Candlelight Vigils attracted wide public recognition and they became an important, and unique, form of activism adopted by the AIDS movement. Both these memorials contributed to the way in which knowledge about people with AIDS was constructed in the public imagination. The act of creating a memorial asserted that people who had died from AIDS, regardless of whether they were homosexual or heterosexual, deserved to be respected and remembered. In this way, the memorials were a public rejection of the stigma associated with AIDS.
Chapter One: Studying Social Movements as a Theory of Knowledge

This thesis is a study of the role that gay activists played in the social and political response to HIV/AIDS in Australia. It is a study of a social movement. I explore the organisational form that the AIDS movement adopted and the tactics they used. The central focus of the thesis is what could be described as an assessment of the ‘cultural legacy’ of the AIDS movement. I demonstrate the influence of AIDS activism on dominant social perceptions of gay men and lesbians. I also study the relationship between AIDS activists and the medical profession, looking at how the dynamics of this relationship were central to the medical, social and political response to HIV/AIDS. There are two core bodies of literature that frame this study: social movement theory and the sociology of knowledge.

Defining a Social Movement

There are no clearly definable elements that mark a social movement, and whether or not particular forms of collective action constitute a ‘movement’ is a source of much academic debate. But there are some key ‘social movement features’ that have been identified by a number of researchers. Firstly, many theorists agree that an analysis of movement tactics must be at the basis of any definition. Burstein et al. (1995), for instance, construct a definition of social movements based on the willingness of actors to use “non-institutionalised tactics at least part of the time”. They explain social movements as “organised, collective efforts to achieve social change”. Accordingly, Burstein et al. argue that social movements must not be bound to any institutional structures or have formal alliances to a political party, institution or government (Burstein et al., 1995:278).
to the movement through their relationship with HIV/AIDS itself or because they broadly identified with the population group most affected in Australia – namely gay men. AIDS activists utilised a range of tactics, from formal lobbying and participation in government advisory bodies to street demonstrations and pickets.

The response of community actors to AIDS was diverse. Some people volunteered for care and support roles, establishing charities and agencies that provided at-home care for people with AIDS-related illnesses. Others became more directly politically engaged, lobbying for increases in government funding and action around HIV/AIDS. Education and HIV prevention initiatives were also a major focus of community action, with many people involved in the production of HIV information materials and running ‘safe sex’ campaigns. When I refer to the ‘AIDS movement’ as an identified group I seek to encompass the full range of initiatives taken up by activists. This is not an attempt to simplify or ignore the diversity of community responses to AIDS, in fact within the thesis I outline the impact of different tactics and strategies employed by community activists. Defining the community response to AIDS as a social movement, however, is an expression of my assertion that analysis of the history of the AIDS movement in Australia can contribute to existing social movement theory and research.

**Social Movement Theory in a Nutshell**

The breadth and detail of the literature on social movements is too vast to summarise here and what I present below is by no means an exhaustive account of social movement theory. It is more of a ‘nutshell’ version, intended to introduce a theoretical framework for the thesis and to define the benefits and limitations of
existing social movement theory for this study. The theoretical framework I have
developed draws on and moves through, but does not end with, social movement
theory.

Contemporary social movement theory has developed around two theoretical
traditions – the European New Social Movement Theory and the North American
Resource Mobilisation Theory (RMT). Both theories explain the emergence, and
significance, of contemporary social movements in modern society – particularly the
new radicalism of the 1960s and early ’70s. While these are not homogenous bodies
of thought on the subject, the broad tenets of one or other of these approaches have
influenced social movement research in the recent past.

Much theory produced in the RMT tradition is based on an interest in the question of
why the 1960s generated such momentum for social movements when other decades
had not. Researchers reason that the nature of social grievances in the 1960s had not
changed substantially from previous decades, therefore other factors must have
facilitated the translation from grievances to collective action. John McCarthy and
Mayer Zald propose the idea that the emergence of social movements requires
particular material and organisational resources. They suggest that the post-WWII
expansion of wealth and technology in western countries enabled the growth of this
McCarthy and Zald introduce the concept of political opportunity structures (or
political process theory) to explain the significance of local factors that assist a
movement to mobilise or to be successful in achieving its goals. Political opportunity
structures may include such things as changing alliances among political elites, the
emergence of movement sympathisers in powerful positions, the relative accessibility of the political system or other factors that provide resources to assist a movement to develop and gain power. Some studies also look at the internal resources available to a movement through such things as its organisational form, access to material resources or control of symbolic resources such as moral authority and solidarity (Della Porta and Diani, 1999:8; Swain, 2002:10). Political process theory provides a neat empirical frame for the study of social movements, suggesting that movements must be studied in the context of social, political and economic conditions. Given that political opportunities are considered to be localised, the concept is the basis of many comparative studies undertaken on social movements by resource mobilisation theorists (see for example, Kitschelt 1986; Tarrow, 1998).

European theorists of new social movements (NSM) offer a different view of the rise of social movements in the 1960s, positioning them as a reaction to the contradictions of modern industrial capitalism. The increases in individual wealth and autonomy, which had been a feature of the post-WWII period, ushered in new forms of societal organisation and changing moral codes, precipitating wide-scale social unrest. In this period of economic boom, labour market conflict no longer formed the basis for social grievances and collective mobilisation. Instead, people began to mobilise around ‘post-material’ concerns such as quality of life, environmental protection and social justice. NSM theorists observe that the constituency of new social movements does not emerge from a social class or in response to the structural position of actors – or structural inequality. Rather, political consciousness and motivation for collective action is associated with an
individual’s immediate personal experience and sense of identity, or an intellectual commitment to addressing social problems. Therefore the demands made by new social movements tend to focus on broader principles of democracy and human rights, rather than the state or economy (Della Porta and Diani, 1999:11; Touraine, 2002:89; Melucci, 1989:19; Swain, 2002:8; Pichardo, 1997:412-414; Taylor, 2000:271).

NSM theorists look at shared identity as a basis for mobilisation, often citing the civil rights and gay movements as examples of collective action that consciously engages in ‘identity politics’, the aim of these movements being to challenge or change dominant societal perceptions of movement participants (Stryker, 2000:23; Britt and Heise, 2000:252). As such, NSM theory tends to focus on the cultural rather than political significance of social movements. Theorists position movements as struggling for symbolic space – that is, cultural space to express new forms of social identity (such as ‘gay’ identities) or space to articulate new values and moral principles (such as racial equality). In this sense, it is argued that the field within which new social movements operate has shifted toward civil society, away from the political sphere and engagement with the state (Canel, 1997).

This study owes much of its ‘intellectual debt’ to both RMT and NSM theory. RMT, for example, suggests an empirical approach based on analysis of the local political and economic conditions that may have supported movement development. In the thesis, I discuss several ‘political opportunities’ that were afforded to the AIDS movement, such as a supportive Federal Government and pre-existing organisational structures among the gay community that could be mobilised in response to
HIV/AIDS. I also draw from NSM theory, engaging the concept of collective identity. The AIDS movement wasn’t mobilised simply around the issue of material resources but emerged as gay men sought to reframe a stigmatised identity in the face of HIV/AIDS (Gamson, 1989:353).

As described above, social movement theory informs my explanation of collective mobilisation around HIV/AIDS. Neither RMT nor NSM theory, however, provides a full framework for this study, indeed it might be more apt to describe their influence as ‘empirical pointers’.

The Impact of Social Movements

A limitation (or perhaps frustration) with NSM theories and RMT is that the primary focus of both of them is the social/political conditions that generate collective mobilisation and the process by which mobilisation occurs (the ‘how’ and the ‘why’ of mobilisation) rather than the ‘outcomes’ or achievements of movements (Giugni, 1998:373-4)\(^\text{5}\). A discussion of outcomes is, in many ways, central to this thesis. Writing some 20 years after the first cases of AIDS were identified in Australia and the first waves of activism were seen in response, a starting point for this study was the question of what impact the AIDS movement has had on the Australian social landscape. Is there now a different perspective on HIV/AIDS because of the

\[^5\] Some studies that sit broadly within a RMT framework have sought to assess the tangible achievements of movements such as changes in legislation or redistribution of material goods. ‘Success’ in this context is often defined in terms of formal government response to the demands of the movement (Melucci and Avritzer 2000: Giugni 1998).
movement? Has movement action improved the lived experiences of gay men, lesbians and people with AIDS?

The focus on identity and civil society in NSM theory opens some conceptual space for a study of the cultural impact of social movements. Melucci and Avritzer, for instance, argue that social movements increase opportunities for democratic participation of marginalised groups. They suggest that social movements create a forum through which new or marginalised identities, and the views of marginalised groups, gain visibility (Melucci and Avritzer, 2000:521). In this context, the creation of a public presence in itself is what is significant, not the level of formal political or material change a movement is able to effect (Melucci and Avritzer, 2000:509). While Melucci and Avritzer do not suggest a framework for empirical analysis, they do introduce the idea that the form of social change that can be attributed to movements is a shift in the social position of groups. Movement action can create a more visible public presence for social groups and the ideas and values they stand for. In this sense, the impact of movements is not just in the formal political arena but also in the make-up of culture and everyday social life. By opening new ‘cultural space’ for previously marginalised social groups, movements introduce new ways of viewing the world – new knowledge – and a new social reality for movement constituents.

A similar idea is introduced by Sandra Grey through her argument that social movements can generate what she calls ‘discursive advantage’. That is, social movements are not just struggles for material resources or increased access to
political decision-making, but conscious efforts to recast public perceptions and social knowledge. Grey writes:

Social movements are involved in battles for cognitive space, fights for cultural stakes and for different meanings to be adopted. In this sense, social movements attempt to change the frames of politicians, bureaucrats, the media, and members of the public not just those of social movement activists and potential activists … When and how movements add to or change the cultural stock are important dimensions in understanding social change in general (Grey, 2002:6).

Such a discursive focus of course raises the methodological problem of how to attribute the actions of social movements to observed change (Giugni, 1998:385). Grey suggests that the analysis of public discourse is a mechanism to track the influence of movements, as it can follow shifts in the way “terms are defined and the issues are framed” (Grey, 2002:7). While Grey focuses exclusively on the influence of social movements on the debate around public policy, she does emphasise that social movements have a role to play in the construction of social knowledge more generally.

**Movement Frames: The Production of Knowledge**

Central to the abovementioned “battles for cognitive space” is the means by which social movement actors define or articulate their goals and values (Grey, 2002:6). In other words, the way in which social movement actors view the social and political world determines the nature of the changes – whether cultural or material – that they
seek to effect. Social movement ‘framing’ (or the process by which social movement actors come to frame the issues with which they are concerned) is a major theme in social movement studies. Originally attributed to the work of Robert Snow and David Benford, a movement frame is defined as movement actors’ collective interpretation of social conditions, or set of beliefs, that legitimates the need for social change and inspires people to participate in collective action. Frames also articulate the goals of the movement – the changes movement leaders seek to achieve (Snow and Benford, 1992:137; McVeigh et al., 2004:656). Generally, movement ‘frames’ are a recasting and reapplication of existing knowledge (Tesh 2000:120; Benford and Snow, 2000:613). The civil rights movement, for example, framed its political demands in the discourse of religious morality, connecting Christian values to a sense of human rights and ethnic identity. The ‘cultural frame’ of the civil rights movement both inspired people to become involved in the movement and presented a new way of understanding the social position of African Americans (Benford and Snow, 2000:614). Similarly, Sylvia Tesh points out that by creating a central frame of injustice, previously unconnected events can become a target for movement action. The women’s movement for example, brought issues such as pornography, abortion laws and workplace inequality within the singular frame of gender injustice and inequality (Tesh, 2000:125). Movements are therefore ‘carriers and transmitters’ of new ideologies more broadly (Tarrow, 1992:188). Tesh argues that this point is often lost by social movement researchers who use ‘framing’ as a concept to understand how movements have mobilised rather than the role of movements in the production of social knowledge.
In making this move, frame theorists neglect what may be a social movement’s most important achievement. If a movement actually creates a set of ideas that give new meaning to the world, if it spreads those new ideas so widely that they become familiar to the general public, ... who then re-understand the events in their lives ..., the movement has accomplished a great deal more than mobilise people into protest groups. It has initiated social change (Tesh, 2000:126).

Tesh emphasises the ability of social movements to inspire people to adopt a different view of the world and to reveal the political bias that may lie behind knowledge and values that are taken for granted – ‘everyday knowledge’ (Tesh, 2000:137). Ron Eyerman and Andrew Jamison articulate this as the ‘cognitive praxis’ of movements. They argue that movements can be seen not only as challenging existing power structures but as a constructive force, actually producing new knowledges and new ways of viewing the social world (Eyerman and Jamison, 1991:49).

Eyerman and Jamison propose that by studying the ‘cognitive praxis’ of movements, researchers can track how movements reframe and rearticulate knowledge, or give greater political attention and moral legitimacy to particular ‘ways of knowing’ (Eyerman and Jamison, 1991:43). The environment movement, for example, took ideas regarding ecology and ecological connectedness that had been emerging in the scientific arena and reframed them as issues of politics and social justice (Tesh, 2000:125). This brought a moral and political discourse related to the environment
into public consciousness. Issues such as fishing, forestry, waste disposal and water quality became a concern for policy makers and social scientists rather than problems with relevance only to science or industry. In other words, the environmental movement created a new cultural frame for understanding the environment (Tesh, 2000:125).

The notion of social movement framing informs the theoretical structure of this thesis. The study proposes a method of ‘reading’ the AIDS movement historically, in the context of social knowledge about both homosexuality and medicine. That is, I examine how the cultural frame of the AIDS movement developed, and how this frame translated into the (re)construction of social knowledge about homosexuality and people with HIV/AIDS. I also look at how the cultural frame of the AIDS movement brought it into contest with the medical profession. Medical knowledge has historically held a high level of legitimacy and autonomy in modern societies. The organised AIDS movement imposed on this autonomy, demanding that the knowledge held by lay people, and affected communities, was also a legitimate source of expertise in relation to clinical research and treatment. In this sense, the study sits within the body of work on the sociology of knowledge – detailing the impact of a group of ‘lay people’ or ‘lay activists’ on medical knowledge and also the role of the AIDS movement in the production of social knowledge about homosexuality. The study essentially explores the relationship between social movement theory and the sociology of knowledge.
Social Movements and the Sociology of Knowledge

The basis of the sociology of knowledge is the concept of knowledge being both reflective and constitutive of social order. Knowledge is not pre-determined by some innate source, or revealed though spiritual means as religious texts would hold, but constructed through social relations. Studies in the sociology of knowledge involve tracing the historical trajectory of bodies of both formal and informal knowledge – from scientific discourse and political and religious ideologies, through to cultural and organisational patterns of thought and everyday ‘commonsense’ ideas. The sociological task is to uncover how social conditions have determined particular patterns of thought. Sociologists also seeks to comprehend the impact of particular ‘ways of understanding’ (and knowing) the world on social and political structures and on individual’s public and private lives (Abercrombie, 1980:6; Swidler and Arditi, 1994:306; McCarthy 1996: 2-12).

Suggesting a relationship between social movements and the production of knowledge, as I do in this thesis, establishes the need to look at the ‘cognitive praxis’ of movements in the context of competing social forces. By definition social movements have a social change agenda – they wish to ‘move’ or change the existing order in some way. Movements therefore sit in opposition to existing political and cultural ideas, and the social/political groups that support them. The strategic intent of a social movement is to influence people’s perception of the world around them by bringing its cultural frame to the forefront of public consciousness, over that of its political opponents. The sociological questions raised by this are: how and why the cultural frame of a social movement becomes a dominant influence over public consciousness; and how and why does the cultural frame of a social
movement attain prominence over the cultural frames of other social/political groups in any one historical period? (Eyerman and Jamison, 1991:49; McCarthy, 1996:3).

Karl Mannheim positions knowledge as a phenomenon determined though group experiences and interests. That is, common social location is what moulds people's ideas and patterns of behaviour. Much of Mannheim's research was based on the belief that the social sciences were in a position to resolve stagnant political conflicts through exposing the material and structural interests that influenced the ideological and political positions of social groups. He believed that if the structural basis of conflicts was revealed, they could be more easily understood and overcome (Abercrombie, 1980:38; Dant, 1991: 10-11: Mannheim, 1970: 111). Some consider Mannheim's objective for the social sciences as overly ambitious. Others consider his theory to be overly simplistic, arguing that knowledge is produced through multiple forces and not only related to social location (Dant, 1991: 10; Swidler and Arditi, 1994:306). Mannheim does, however, introduce the idea that knowledge is produced through tension between competing interests. In other words, Mannheim captures a sense of the "political atmosphere into which knowledges are generated" which is useful for a study of social movements (McCarthy, 1996:2).

A study that explores the relationship between the sociology of knowledge and social movements, is effectively a study of the relationship between power and knowledge. The role of social movement actors is to gain sufficient 'power', in relation to other social groups, to influence social reality (Lovell, 2004:51; Crossley, 2003:46 and 57). 'Knowledge' in this sense is the object of political struggle. As Pierre Bourdieu writes:
Knowledge of the social world and, more precisely, the categories that make it possible, are the stakes, par excellence, of political struggle, the inextricably theoretical and practical struggle for the power to conserve or transform the social world by conserving or transforming the categories through which it is perceived (Bourdieu, 1985:729).

Much of the social history of HIV/AIDS in Australia can be explained in terms of the relationship between various social actors with an interest in HIV/AIDS. The AIDS movement struggled for its ‘cultural frame’ to gain public visibility and acceptance within the context of a range of competing ideas and assumptions about these issues. In line with this, this study looks at the relationship between the AIDS movement (community activists), the Australian State (mainly the ministerial level of the federal and state governments, but also the bureaucracy) and the medical profession. The divisions between these three groups are by no means neat: in fact the role of individuals who cross the boundary between doctor and activist, or bureaucrat and activist, is part of my analysis of the AIDS movement. But the relationship, whether antagonistic or collaborative, between these three groups was an important feature of the AIDS response as virtually all policy and practical responses to HIV/AIDS had to be negotiated between these groups. The study looks at how knowledge about HIV/AIDS and its treatment and prevention was a product of shifting social forces.

6 Robert Ariss (1997) adopts a similar framework, which he refers to as the ‘state–medicine–community triad’. The three poles of the triad Ariss is referring to are: the interventionist Australian state: the biomedical construction of homosexuality; and the counter-discourse to this that was produced by the gay movement and the community.
between them (Blain, 1994:808). The thesis also explores how the AIDS movement was able to gain enough social power, within the context of these relationships, to influence knowledge about HIV/AIDS (Rose, 1994:50; Ellingson, 1995:107).

**A Frame of Knowledge and Emotion**

Gay identity was central to the mobilisation of the AIDS movement. The history of gay and lesbian discrimination meant that when AIDS emerged gay men did not trust mainstream health services and the government to provide support for people with HIV/AIDS, or to protect the civil rights of gay men. There were fears that the rights and freedoms of gay men and lesbians would be lost. The ‘frame’ of the AIDS movement was a product of the intersection between gay and lesbian history and the fear, grief, anger and mistrust that swept through gay community as the number of AIDS cases and AIDS-related deaths increased. I propose that the ‘cognitive praxis’ of the AIDS movement can only be fully understood in terms of both the intellectual form of the movement frame (the political goals of the movement and social values it espoused) and the personal and emotional reaction of gay men to AIDS. In other words, emotion, history and strategic intent all form part of the development and form of a social movement.

There is much academic work on the relationship between organised, collective action and emotion. Implicitly or explicitly, all social movements appeal to emotion in some way. Feelings of fear, anger, indignation or joy are emotions that can inspire and galvanise collective action. Rituals and demonstrations are also used to stir up emotional sensations and affirm connection with the group (Taylor and Rupp, 2002:145; Goodwin et al., 2001:16). Early academic work on emotion and collective
action focused on emotional reactions to events that led to crowds spontaneously reacting in anger or hatred ‘in the heat of the moment’ (Goodwin et al., 2001:5). More recent scholarship has sought to examine the relationship between emotions that inspire collective action and the cognitive, rationalised decisions of movement actors. James Jasper, for instance, uses the term ‘moral shock’ to suggest that what may motivate a person to take political action are feelings of moral outrage or indignation towards events – such as anger following an environmental disaster or offence over government decisions. Jasper suggests that emotional reaction and political analysis work in conjunction; morals are a culturally or cognitively framed assessment of the situation but these generate an emotional reaction (anger, indignation) (Jasper, 1998:409; Goodwin et al., 2001:13).

Of further interest to social movement scholars is the question of how movement actors work to maintain the emotional reaction of groups and direct it towards a political target and substantive goals. Moral outrage sparks an emotional response which social movement organisers then steer towards a sustained political strategy (Jasper, 1998:409). As a movement progresses, the sensation of empowerment and elation that often accompanies involvement in collective protest can serve to maintain motivation for movement action. As Debra Gould describes, emotions can be mobilised in a manner that “nourishes resistance” (Gould, 2000:xvii).

Emotion is a consistent theme that emerged throughout the research for this study. In the early chapters I look at the relationship between fear and the mobilisation of the AIDS movement. Movement actors were motivated to begin organising their
response because they were fearful, not only of AIDS itself but also of the potential social and political repercussions of AIDS. In later chapters, the issue of trust and mistrust between AIDS activists and the medical profession was a factor in the negotiation of AIDS policy and practice. In Chapter Seven, I look more closely at emotion through a discussion of the relationship between grief and stigma, exploring the way in which the AIDS movement challenged homophobic discrimination and stigma around AIDS through the creation of memorials to people who had died from AIDS.

I do not wish to make in this thesis a generalised statement about the role of emotion in social processes. As Jack Barbalet has written: “Rather than treat emotions in general it is absolutely necessary to treat particular emotions” (Barbalet 2001: 16). I do, however, suggest that the relationship between emotion and the development of a social movement frame is not coincidental. That is, social movement frames are a product of the historical location of their constituents, which is born out in both their intellectual and emotional reactions.

**Conclusion**

Pierre Bourdieu uses the term ‘doxa’ to describe the basic assumptions that underpin social knowledge, doxa being the framework *through* which people think, rather than their actual thoughts. According to Bourdieu, the potential for new, or previously unspoken, ideas to enter public consciousness is created through a change in objective social conditions. That is, the assumptions that underlie the way we think are only questioned when something material forces them to be made visible (Bourdieu, 1977:166). This thesis looks at how HIV/AIDS created the conditions by
which new ways of thinking about homosexuality became possible. The emergence of this new virus caused enough of a rupture in the social world for activists to reconfigure old ‘ways of knowing’.

This study proposes a method of ‘reading’ social movements that is historically grounded, placing a movement in the context of the production of social knowledge. The nature of ‘knowledge’ discussed in the thesis is both the professional, scientific knowledge that was at the heart of tension between AIDS activists and medical professionals, and the ‘everyday’ perceptions and ideas that informed mainstream attitudes toward gay men and lesbians. The thesis draws on social movement research to comprehend the nature and form of the movement’s mobilisation; in particular, to assess how the AIDS movement developed as a significant social and political force. But ultimately what is presented here is the idea that analysis of social movements has much to offer studies of the sociology of knowledge.
Chapter Two: Hermeneutics of Activism: Explanation of Method

My general approach to this study is not one that seeks to determine cause or effect of the AIDS movement in a positivistic sense. Rather, the study aims to locate the AIDS movement historically, placing it in the context of the construction of social knowledge – an approach that could be described as ‘hermeneutic’ (Eyerman and Jamison, 1991:64). The study looks at the broad social and historical context in which the AIDS movement developed in order to assess how these conditions informed and motivated movement action and how the ‘frame’ of the movement came to intersect with existing social knowledge.

Genealogy of a Movement

The methodological approach of this study draws on Foucault’s genealogical method in that it traces a social history of discursive constructions of knowledge (Dant, 1991:121). While Foucault does not articulate a method or methodological framework, his work suggests a particular way of using historical analysis to reveal how present social practices have come into being – a ‘history of the present’, or what Rose calls “an act of decomposition” (Rose, 1994:50; Blain, 1994:809). Foucault’s histories of the present are studies in the relationship between knowledge and socio-political power. They reveal the path by which social forces established particular forms of knowledge and discourse. Stephen Epstein describes such an approach as concerned with “a recovery of the immanent rules of what is sayable and

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7 See for example the method adopted by Foucault to trace the history of what he terms the ‘repressive hypothesis’ of sexuality in *The History of Sexuality Volume I* (Foucault 1976) and his study of medical knowledge and scientific classification of the body in *The Birth of the Clinic* (Foucault 1994).
unsayable, thinkable and unthinkable” (Epstein, 1996:357; Rose, 1994:50). This method sets up particular assumptions about the nature of social reality. That is, studying the history of the present assumes that social reality is changeable and historically contingent (Epstein, 1996:357; Quibell 2004: 92).

In the hands of Foucault, a genealogical method is a study of power, not a neutral tracing of history. Of central concern in all Foucault’s work is the relationship between power and knowledge. Power lies not in the capacity to constrain or repress others, but in the ability to shape the way people view the world and themselves and to influence what we perceive as ‘natural’, ‘self-evident’ or ‘the truth’. Scientific medicine, for instance, is a powerful force in the modern west because it has profoundly shaped what is considered to be ‘normal’ in terms of human bodies and behaviour. Such normalising discourse leads people to monitor their own selves in accordance with society’s determination of psychological and medical indicators of ‘normality’ (Foucault, 1976; Foucault, 1980; Foucault, 1994). Challenging such discourse would entail confrontation with the material interests that maintain western medical dominance. But, perhaps more fundamentally, it would require a shift in perceptions of what is ‘real’ and ‘normal’ in terms of bodies, health and illness. Foucault would argue that such a shift would not be achieved through ‘liberation’ from Western medicine but through some type of social upheaval that leads to alternative ideas gaining prominence in mainstream thought.

In this study, I look at how the AIDS movement was able to gain enough legitimacy as a prominent social force to contribute to changing negative perceptions of gay men, as well as challenging the dominance of traditional medical knowledge in
public health policy. I explain this using a narrative history approach that details the rise of the AIDS movement in historical context and tracks the development of relationships between AIDS movement actors and other social groups, such as medical doctors and the Federal Government. I argue that the AIDS movement actively produced knowledge about homosexuality, HIV/AIDS and public health. That is, the actions of the AIDS movement weren’t only oriented toward fighting against other social forces, such as the medical profession. Rather, movement actors they were actively engaged in knowledge production (Blain, 1994:811).

Case Studies

The thesis involves a series of case studies, looking at different events in the history of HIV/AIDS in Australia. The case studies have been generated using archival material, interviews (discussed in more detail below) and secondary sources. The purpose of these case studies is to develop the historical ‘story’ of the AIDS movement and to create an interpretation of the ‘cultural frame’ adopted by the movement.

Archival Material

Development of the case studies involved analysis of various materials produced by social movement actors and organisations (flyers, pamphlets, annual reports, publicity materials, newspaper articles and so forth). These provided a sense of the position taken on HIV/AIDS by various community organisations and individuals, the claims they made and the way in which they sought to influence public opinion. The campaign materials, press releases, planning papers, flyers and so forth also
documented the strategies undertaken by the AIDS movement to influence the social and political response to HIV/AIDS.

The Noel Butlin archives in Canberra holds a vast collection of material relating to HIV/AIDS in Australia. The collection is largely comprised of papers donated by individuals and organisations that were directly involved in HIV/AIDS policy and practice. The papers include correspondence, press releases, notebooks, memos, meeting minutes and so forth. The Noel Butlin collection also includes educational materials such as posters, stickers, milk carton campaigns and information booklets, which were produced by the federal and state governments and non-government agencies. I systematically reviewed the following collections:

- General non-government products
- The AIDS Coalition to Unleash Power (ACT UP)
- Bill Bowtell papers (former advisor to Health Minister Neal Blewett)
- Phil Carswell papers (former president of the Victorian AIDS Council, member of NACAIDS, HIV/AIDS policy officer with the Victorian Health Department)
- Geoffrey Harrison papers (HIV activist involved in ACTUP, strongly involved in campaigns around treatment access)
- National Association of People Living with AIDS
- General reference material
Media Analysis

I have used media analysis in some sections of the case study to gain a sense of the public debate and opinion on issues relating to HIV/AIDS. Time and resource limitations meant the study could not involve a thorough content analysis of all mainstream media sources over the time period. Rather, the media analysis was derived from a specific ‘keyword’ search for articles on HIV/AIDS using FACTIVA media database. I also made use of a content analysis of HIV/AIDS-related articles conducted by Deborah Lupton in 1993 (see Lupton, 1993). As well as this I systematically searched collections of press clippings held in the Noel Butlin archives, the ‘Media Watch’ collection donated to the National Library of Australia by the West Australian AIDS Council (WAAC) and the comprehensive volumes of media clippings (collected through the years 1981–1990) held by the Australian Lesbian and Gay Archives in Melbourne. Many of these collections are the archived copies of the daily ‘media watch’ packs, that were compiled by professional media monitoring services employed by AIDS organisations in the 1980s and early 1990s (before media began to be electronically archived).

As well as the mainstream press, gay community newspapers have been used as both a source of factual/historical information and as a means to track community debates. AIDS organisations and individuals made regular use of community publications such as the Sydney Star Observer, the Melbourne Star Observer, the National AIDS Bulletin, Outrage Magazine and Campaign Magazine to voice their opinions and provide information about HIV/AIDS to the gay community. As such, these sources are an effective means of uncovering the position or positions being put forward by the AIDS movement at any one time.
The media analysis conducted in this thesis is in part used to ascertain historical ‘facts’ but also to develop an idea of how the identities of AIDS activists were constructed and represented to the public. My assumption is that what is expressed in mainstream media will reveal shifts in public perceptions of HIV/AIDS and the people affected by it (Gamson and Modigliani, 1989:2; Lawler, 2004:114). Given that a majority of the general heterosexual public had limited personal experience with either gay men or people with AIDS, the media was their central means of acquiring knowledge. Kaye Wellings, for example, argues that the way in which the media constructed images of HIV/AIDS was instrumental in determining how the general public perceived their level of risk with regards to HIV transmission (Wellings, 1988:88). Similarly, in their study of attitudes to HIV/AIDS, Kippax et al. cite the media as an important source of information through which people formed opinion and beliefs about HIV/AIDS and HIV positive people. They write:

It was clear from the group discussions that people obtained information and constructed meaning from media sources. News reports were very frequently mentioned either implicitly or explicitly. Cases such as Holly Johnson⁸, Charleen⁹, the dentist in Miami who infected his patients, the prison officer...

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⁸ Holly Johnson was child who was infected with HIV by her mother, who had acquired the virus through a blood transfusion. The case received a great deal of media attention when Holly’s father made a legal claim for compensation. Holly Johnson died in 1990 (Riley 1990:9).

⁹ Charleen (sometimes spelt Sharleen) was a sex worker who achieved infamy when, in 1987, newspapers ran a story about her continuing to have sex with clients despite knowing her HIV positive status. The NSW Minister for Health, Peter Anderson, wanted to use the Public Health (Proclaimed Diseases) Amendment Act to detain her, but it was not until two years later, in 1989, following her appearance on the 60 Minutes current affairs show, that the Department of Health arrested her, enforcing the Public Health Act 1903 which enables health authorities to detain an infectious patient for treatment. This led to public outrage among AIDS activists and civil libertarians.

Footnote continued next page
who was injected with a blood filled syringe ... were mentioned. When such cases were mentioned, the other group members had no difficulty in identifying them (Kippax et al., 1991:31).

An inquiry by the NSW Anti-discrimination Board in 1992 also concluded that the media plays a central role in determining public attitudes toward HIV and AIDS. The inquiry report stated that the media can be responsible for either legitimising discrimination or promoting positive public attitudes (NSW Anti-Discrimination Board, 1992:17).

The AIDS movement employed campaign strategies that deliberately sought to influence media portrayals of both gay men and HIV positive people. Activists also worked hard to position themselves as legitimate media spokespeople on HIV/AIDS-related matters. Kippax et al. note that the media tend to privilege information derived from medical sources over that of AIDS activists or non-medical sources.

Because of the historical authority and respect accorded to the medical profession and the public's high regard for science, the [general public's] knowledge base tends to reflect the [medical profession's] more readily than it does the views of the dissenting enclave [gay men and social scientists]. The mass media undoubtedly play a role in selecting and filtering the body of knowledge available to the public, and this will also reflect the same

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and was a high profile media story for some weeks. It was the first act of compulsory quarantine of an HIV positive person ever seen in Australia (Perkins 1991).
The interviews were semi-structured, focusing on participants' memories of key issues or campaigns, including the issues of blood donation, access to HIV medications and the question of a 'medical model' versus a 'community education' approach to public health and HIV prevention. Interviewees were also asked what they believed to be the most significant role played by community activists in response to AIDS and how they perceived the relationship between government, medical professionals and community activists.

The National Library of Australia holds the transcripts of a series of interviews that were conducted as part of the library's oral history project, 'Australia's Response to AIDS'. The interviews were conducted with key policy makers, activists and doctors. With permission, I accessed the transcripts of a number of these interviews.

The interviews I conducted were transcribed and analysed, along with the interview transcriptions from the National Library of Australia, for key themes. Rather than being presented separately, the findings from this interview material have been integrated with information from archival and secondary sources to form a central part of the case studies. Throughout the thesis, transcribed quotations from these interviews are italicised to distinguish them from quotations borrowed from other published sources.

A brief biography of each person I interviewed for this study and those whose interview transcripts I accessed through the National Library of Australia's Oral History Archives appears below. Appropriate permission was sought for each
interview and transcript cited in the thesis. My study, including these interviews, was approved by the Australian National University Human Research Ethics Committee.

Face to face, indepth interviews were conducted with the following people:

- **Dennis Altman** is an academic and activist who has written extensively on HIV/AIDS in both Australia and the USA. Altman was in the USA for much of the early 1980s, but upon returning to Melbourne in the later part of the decade was involved with the establishment of the Victorian AIDS Council.

- **Bill Bowtell** was the senior advisor – Chief of Staff and Chief Political Advisor – to the Australian Minister for Health, Dr Neal Blewett from April 1983 (beginning four weeks after the Labor Government had been elected and Blewett had been appointed Health Minister). Bowtell worked in this position until 1987. Bowtell was also well connected to the gay community and community AIDS organisations.

- **Phil Carswell** was the founding president of the Victorian AIDS Council (VAC). He has spent over 15 years working in the AIDS sector and was the first openly gay man to work at the Victorian Health Department when he joined as a program officer in the Department’s first AIDS section. Throughout this period Carswell was also active in the community, helping to establish the AIDS Trust and the Australian Federation of AIDS Organisations (AFAO), working with the AIDS Memorial Quilt and continuing his involvement with the VAC. He was a foundation member of National Advisory Council on AIDS, representing the VAC.
• *Levinia Crooks* is a psychologist who became involved in the AIDS movement in the mid-1980s through her work on a research project that was looking at the care and support needs of people living with HIV. She has also been involved with the AIDS Council of NSW (ACON) and was the first executive officer for the National Association of People Living with AIDS (NAPWA). Crooks is currently the Executive Officer of The Australian Society for HIV Medicine (ASHM) and has a long-standing involvement with the Bobby Goldsmith Foundation.

• *Ken Davis* is a former official with the Community and Public Sector Union and currently works for APHEDA: Union Aid Abroad. Davis has been active politically around AIDS issues since the early 1980s, both though his involvement with the union movement and through his work with various AIDS organisations including ACON.

• *David Lowe* was a participant in both the community and government response to HIV/AIDS in Australia. He was involved with the AIDS Action Committee in Sydney, which later became ACON. He also worked as Community Liaison and Conciliation Officer with the NSW Anti-discrimination Board in the mid 1980s before moving into the newly established AIDS Bureau in the NSW Health Department as a Senior Policy Analyst in 1987. Lowe later became Director of the NSW AIDS Bureau, a position he held until the mid-1990s.

• *Professor David Plummer AM* has been involved with the AIDS response in Australia since 1983 as a medical physician and community activist. Plummer was the first National President the Australian Federation of AIDS
Organisations (AFAO). He was also a long-serving member of the peak ministerial advisory body, the Australian National Council on AIDS, Hepatitis and Related Diseases (ANCAHRD). Plummer was actively involved in the establishment of the VAC and the Gay Men's Community Health Centre (GMCHC).

- **Ian Rankin** has been involved in AIDS politics since the early 1990s. He is a former president of the AIDS Action Council of the ACT (1995 - 97), former convener of People Living with HIV/AIDS (PLWHA) in the ACT, former President of the NAPWA (1997–98), and Convener of PLWHA ACT. He is currently a member of the ACT Sexual Health, HIV/AIDS, Hepatitis C and Related Diseases Ministerial Advisory Council and President of AFAO.

- **Prue Power** was an advisor on health policy to the Minister for Health, Housing and Community Service, Brian Howe, from 1990–1992. She oversaw the implementation of the Baume Review into pharmaceutical access in Australia.

- **Bill Whittaker** is a long-term activist. Prior to his involvement with HIV politics, Whittaker was president of the Sydney Gay and Lesbian Mardi Gras. He then went on to the position of executive director of ACON and was a founding member of NAPWA. He was also involved in the establishment of the AFAO.

- One interviewee wished to remain anonymous. This person is a medical doctor with a long professional history in HIV medicine.
Interviews transcripts I sourced from the National Library of Australia Oral History Archives are listed below.

- **Dennis Altman** (as above)
- **Professor Peter Baume** is the former head of the School of Public Health at the University of NSW and former Liberal Senator for New South Wales. In the mid-1990s Professor Baume chaired a review into the therapeutic goods administration which had direct relevance for emerging HIV therapies.
- **Don Baxter** is a community activist. He is a former president, and Executive Director, of the AIDS Council of NSW. He is currently the Executive Director of AFAO.
- **Bruce Brown** was an American activist who came to Australia from San Francisco in the mid 1980s. Brown was instrumental in the establishment of the first Australian chapter of AIDS activist group the AIDS Coalition to Unleash Power (ACT UP).
- **Victor Carroll** is the former editor of the *Sydney Morning Herald*. In this interview Carroll discusses the Herald’s reporting on the gay movement in Sydney.
- **Professor John Dwyer** is the Clinical Director of the Prince of Wales Hospital and was a member of the National Advisory Committee on AIDS (NACAIDS) in the 1980s.
- **Steven Mark** is a lawyer and former President of the NSW Anti-Discrimination Board.
• Mrs Jennifer Ross is the former Executive Director of the Haemophilia Foundation of Australia. Mrs Ross was a foundation member of the National Advisory Council on AIDS in the 1980s.

• Terry Thorley is a former national coordinator of the Australian Quilt Project.

The Study of HIV/AIDS

The impact of HIV/AIDS in Australia has been widely studied and there is a general consensus on the important role played by community-based actors in the social and political response to HIV/AIDS. In particular, these studies have highlighted the significance of the lesbian and gay liberation movement in facilitating the early community response to AIDS (see Sendziuk, 2003; Ariss, 1997; Altman, 1988, 1992 and 1994; Ballard, 1998; Dowsett, 1998; Lewis, 1998; Rawling, 1998; Woolcock, 1999). This literature has informed my analysis and provided guidance to the focus of my research. However, while there are several studies that have applied social movement theory to various elements of North American AIDS activism, Australian AIDS activism has not been widely used as a case study by social movement theorists. More commonly, the response to HIV/AIDS in Australia is

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10 A number of authors have looked at the social movement potential of American chapters of the AIDS community organisation ACT UP (see, for example, Elbaz 1995, Gamson 1989, Gould 2000). Other studies look more generally at the mobilisation of AIDS activists in America and Canada (see, for example, Brown 1997, Orsini 2001, Siplon 1997).

discussed in terms of the model of governance it produced. The community/government partnership adopted by the Australian Federal Government supported community involvement in AIDS policy decision-making. The government also provided funds to enable community groups to play a leading role in HIV/AIDS prevention initiatives. Involving the affected community in the way that the Australian Government did represented a unique and widely lauded approach to the management of an infectious disease. As such, the Australian HIV/AIDS experience has provided a rich case study for public policy studies (see for example, Ballard 1992, 1998, 1999; Edwards 1997; Misztal 1990). The Australian Federal Government also supplied generous funding for the study of the social aspects of HIV transmission and prevention. As such there is a large, and invaluable, volume of sociological and psycho-social work on factors that contribute to the vulnerability of individuals or groups to sexually transmitted infections\(^{12}\). Other studies have looked at whether the efforts of gay community actors have translated to reduced rates of HIV infection (see for example Kippax et al. 1993). Sociologists have not, however, taken up the issue of the gay community response to AIDS in Australia by way of a study of social movement activity or the sociology of social action.

\(^{12}\) The volume of work in this area is so large it is difficult to provide a concise list of notable publications. There are a number of research centres in Australia which specialize in the study of social issues relating to sexual health and sexuality, each of which has produced an extensive list of publications. See for example, The Australian Research Centre in Sex, Health and Society based at La Trobe University and The National Centre in HIV Social Research based at the University of NSW.
The politics of knowledge about HIV/AIDS, and the way in which various community actors have laid claim to this knowledge, is a theme raised in a number of texts (see Altman, 1994; Epstein, 1996 and 1995; Patton, 1990). Steven Epstein (1996) studies the relationship between American AIDS activists and medical science, working within a ‘sociology of science’ framework. Epstein is interested in the potential for social movement literature to contribute to an understanding of the role of movements in the construction of credible scientific knowledge. Robert Ariss (1997) takes up some similar themes in his Australian-based study, Against Death: The Practice of Living with AIDS. However, Ariss does not engage explicitly with social movement theory, rather he describes his analysis as an anthropology of illness. He looks at the way in which the everyday experiences of people living with AIDS are collectivised, constructing a counter-discourse to biomedicine.

I am certainly not the first to make the point that the gay and lesbian community achieved greater social legitimacy and acceptance as a result of their response to HIV/AIDS (see, for example, Dennis Altman’s 1988 essay, aptly titled ‘Legitimation Through Disaster’). What this thesis seeks to do is answer empirically the question of ‘how’ AIDS activists achieved greater legitimacy for the gay community through the disaster of AIDS. This question in itself raises interesting material for social movement research regarding the way in which movements gain symbolic power and the way in which they can influence the social status and lived experiences of their constituents.
Limitations and Boundaries

In Australia, HIV/AIDS has predominantly affected gay men and it is gay men who comprised the largest activist group that mobilised around the disease. However, the impact of HIV/AIDS was not limited to gay men, and there were several other groups that also became active in the HIV/AIDS sector. Various organisations representing sex workers were very organised around HIV/AIDS from the early 1980s. In Australia, there have been no recorded cases of HIV transmission in a sex industry setting. This can largely be credited to the actions taken within the sex industry. Although it is not a focus of this thesis, the achievements of the Australian sex-worker industry deserve much greater recognition than they currently receive. From late 1984, the Haemophilia Foundation of Australia (HFA) became active around HIV/AIDS and were represented alongside other community activists on the Federal Government’s advisory body, the National Advisory Council on AIDS (NACAIDS). The HFA worked closely with other community-based AIDS agencies, including gay community organisations, on education and policy matters. Additionally, there were (and still are) many community workers and agencies advocating measures to protect injecting drug users from HIV/AIDS. These three groups are all mentioned where relevant, however indepth discussion of their role in the response to HIV/AIDS is beyond the scope of this study.

This thesis looks at the community response to HIV/AIDS from the early 1980s until the mid 1990s. Moving into the late 1990s and early 2000s, the political conditions in Australia became increasingly conservative and the work of AIDS activists tended to be organised more through formal structures than was the case in the 1980s. A thesis devoted to studying this more recent history might consider questions such as
whether or not, under the Howard Liberal Government that took power in 1996, community AIDS organisations have become dis-empowered by their reliance on government funding. Such a thesis could also look at whether professionalisation of the AIDS movement has created a divide between AIDS organisations and the gay community. These are valid and relevant issues, and important questions with regard to the progression of such social movements over time. However, these questions are beyond the scope of the theoretical framework of this thesis and beyond its scope for practical reasons (lack of time and resources).

HIV/AIDS and the Australian State

This thesis looks at the impact of the AIDS movement in both reconstructing public perceptions of gay men and in challenging the dominance of biomedical discourse relating to HIV/AIDS. The major focus of the thesis, therefore, is the role of social movement actors in the history of HIV/AIDS in Australia. While the study looks at the actions of the AIDS movement in relation to the federal and state governments, the focus of the thesis is not how public policy regarding HIV/AIDS was resolved. That being said, the actions taken by the Australian Federal Government in the response to AIDS provide an important backdrop to this discussion and must be acknowledged.

Health in Australia is traditionally the responsibility of state governments. However, when AIDS arrived it was the Federal Government that took charge of developing and implementing policy. There were several reasons for this. Firstly, the nature of the epidemic meant it was politically unsavory and risky territory for politicians. They did not want to deal with issues relating to illegal drug use, prostitution or gay
men. Cost was another concern. In the mid 1980s there were estimates of an epidemic far more widespread than that which eventuated in Australia, and state health ministers were keen to ensure that the Federal Government took major financial responsibility for it (Blewett, 2003:8).

After a long period in opposition, the Australian Labor Party came to power under the leadership of Bob Hawke in 1983. When the Cabinet was appointed, former Rhodes Scholar, Neal Blewett, took up the position of Health Minister. Blewett recalls that in his first briefing as Minister there was some mention of an illness that was affecting gay men, but the issue was not given high priority. At the time, the matter at the top of his agenda was the reintroduction of a universal health insurance system, Medicare. He also planned to institute changes to the Pharmaceutical Benefits Scheme and a revive former Prime Minister Gough Whitlam’s system of community health programs. However, AIDS became a core priority of Blewett’s period as Health Minister over the course of the 1980s (Blewett, 2003:4).

Blewett is broadly credited with being central to the ‘successful’ Australian response to AIDS. It was under his leadership that what came to be known as the community/government ‘partnership’ approach to AIDS was forged. This model involved provision of funds to non-government groups, such as the gay community-run AIDS councils, to enable them to organise prevention and education initiatives at a grassroots level. The model was also applied to other community groups, with
funding, for example, being provided to the Australian Prostitutes Collective and injecting drug user advocacy groups (Ballard, 1998).\(^{13}\)

Establishing a working relationship with affected communities was no doubt a feature of Blewett’s personal political style. However, he was also strongly influenced by his senior advisor, Bill Bowtell, who was personally involved with gay community activism. There were also some political precedents that supported Blewett’s approach. In 1972, when the Labor party had briefly been in power under the stewardship of Prime Minister Gough Whitlam, they introduced a series of community health programs that aimed to improve the accessibility of health care. A NSW consortium called Consumer Health Involvement was established, with several subgroups that looked at issues of improving information to consumers and enhancing consumer involvement in policy decision making (Altman, 1992:64). This program had been scrapped when the Liberal party over government in 1975. However, in 1983 when Hawke was elected Prime Minister there was an expectation, flowing from Whitlam’s influence, that there would be a renewed emphasis on community involvement in health (Crichton 1990: 160; Ariss, 1997:16).

The Commonwealth Department for Health was also about to be thoroughly restructured under a new Secretary, Bernie McKay. The changes were to include greater emphasis on preventative health through a new Health Advancement Division (Ballard, 1989:359). Also in Australia, the Women’s Health Movement had established some models for community involvement and leadership in health and

\(^{13}\) This partnership model had actually first been established in Victoria, when the Victorian Government agreed to fund the development of the Gay Men’s Community Health Centre run by the Victorian AIDS Council (Ballard, 1998).
provided an example of the process by which community advocates were able to gain influence within the government bureaucracy (Ballard, 1992:137; Ariss 1997:17)\textsuperscript{14}. However, despite the existence of these precedents to support Blewett’s approach to HIV/AIDS, it was still a brave move for a government minister to publicly declare his faith in the capacity of stigmatised groups such as gay men and sex workers to take the lead in preventing a major epidemic.

As well as funding community groups, the Blewett Ministry established a structure for consulting the community on AIDS. The National Advisory Committee on AIDS (NACAIDS) first began meeting in 1984, chaired by Ita Buttrose, and included two representatives from the gay community. Representation on NACAIDS was an important political opportunity for the AIDS movement. As one of the community representatives, Don Baxter, recalls:

> The other thing (NACAIDS) did was give those of us who were on there the direct access, personal access to people who were making the decisions. So, while the meetings themselves might have been messy, we always had informal direct links – or even formal ones. I mean you could write to people quite easily and all of that. So, it actually facilitated community sector

\textsuperscript{14}The strategy of the Australian Women’s Movement was to enter the bureaucracy and government – the ‘femocrat’ approach. Prior to HIV/AIDS the Australian Government did not have a precedent for involving a community movement in policy making without those groups becoming part of government structures.
communications to chief decision-makers in a way that never happened in the US or UK or lots of other places (Baxter, 1993).\footnote{Don Baxter interviewed by James Waites for the National Library of Australia Oral History Project, the Australian Response to AIDS TRC 2815/75.}

The community model was politically risky for the Federal Government. At the time there was no precedent for such a model and it involved giving large sums of money to widely mistrusted and stigmatised groups. However, many authors note that the model provided political benefits as well. John Ballard (1998), for instance, argues that the community-funding model adopted by the Australian Government could be considered an effective method of governing 'at a distance'. It allowed the government to claim credits for successes in HIV prevention, while distancing themselves from any materials or initiatives that attracted political or public protest, such as explicit posters produced by the AIDS Councils in their HIV prevention work. This fitted with the longstanding Australian tradition of the use of statutory authorities and royal commissions, autonomous from government, to undertake work which might create political threats (Ballard, 1998). Dennis Altman similarly notes that the willingness of the Federal Government to fund AIDS councils was a reflection both of “political pressure and of a cynical recognition of the usefulness to governments of groups able to perform certain services either more cheaply ... or at arms length” (Altman, 1992:63). However, many people who were involved in the AIDS sector at the time also acknowledge that it simply made sense for the Government to consult with the community. At that stage, the Government was desperate for information about AIDS and the gay community in Australia, whose
media had been reporting on AIDS since 1981, held most of that knowledge (Plummer, 2004\textsuperscript{16}; Bowtell, 2005\textsuperscript{17}; Whittaker, 2004\textsuperscript{18}). Moreover, the partnership that developed between the community and the Federal Government in response to HIV/AIDS was unique, and a testament to the capacity of the gay community to organise their response. As community activist Lou McCallum writes, “The word ‘partnership’ has been used in many areas of national health policy since the relative success of the AIDS partnership, but the partnerships that are developed rarely contain the sort of power and resource sharing that was seen in the response to AIDS” (McCallum, 2003:33).

It is not the intention of this thesis to divert the historical focus from the importance of the decisions made by Neal Blewett and his advisors in response to HIV/AIDS. Indeed the impact of HIV/AIDS would likely have been significantly more devastating in Australia if the government of the day had pursued a more conservative approach to disease prevention. Strategies implemented under Blewett’s stewardship, including involvement of affected communities and implementation of programs such as the needle/syringe exchange (where injecting drug users were given free access to clean syringes), have proven in the longer term to be extremely effective HIV/AIDS prevention measures (see for example, Blewett, 2003; Drummond et al., 2002; Feachem, 1995). A supportive Federal Government also represented an important ‘political opportunity’ for the AIDS movement in that they were afforded a legitimate role in the policy response to HIV/AIDS and funding was

\textsuperscript{16} David Plummer interviewed by the author on 30 August 2004.

\textsuperscript{17} Bill Bowtell interviewed by the author on 28 May 2005.

\textsuperscript{18} Bill Whittaker interviewed by the author on 6 November 2004.
provided for community-run education and prevention initiatives. These points will be discussed in more detail within the study.
Chapter Three: Homosexuality and the AIDS Movement

In 1932, a clinical study into the efficacy of syphilis treatment began in the American town of Tuskegee. When a journalist exposed the nature of the trial in 1972, it became infamous for its highly dubious (many would say criminal) ethics. It was revealed that, as a deliberate part of this study, approximately 400 African American men were denied knowledge of the existence of effective treatment for their syphilis infection — instead being given older, ineffective treatment or no treatment at all, so that the researchers could study the effects of syphilis on African American bodies. As a result, over 100 research participants unnecessarily died from syphilis or its complications, and many infected their wives. Writing about the legacy of the Tuskegee study, James Jones argues that the collective memory of experiences such as this shaped an inherent mistrust among African Americans of medical authorities. This mistrust was obvious when HIV/AIDS arrived. In 1990, a *New York Times/WCBS* TV news poll found that 10 per cent of African Americans “genuinely and definitely” believed that HIV/AIDS had been “deliberately created in a laboratory in order to infect black people”. A further 20 per cent agreed that this could “possibly be true” (Jones, 1992:38-39). Jones explains these poll results, writing:

The attitudes black Americans brought to AIDS were historically constructed … Above all, many black Americans saw AIDS through the prism of race, which brought more than three and a half centuries of white-black relations into focus. Slavery, sharecropping, peonage, lynchings, Jim Crow Laws,
disenfranchisement, residential segregation, and job discrimination were the substance to which many African Americans reduced all American history, forming a saga of hatred, exploitation, and abuse (Jones, 1992:38).

While the history of homosexuality in Australia is very different to that of African Americans in the USA, similar conclusions to those made by Jones can still be applied to the case of HIV/AIDS in Australia. Just as it was with African Americans, the response of the Australian gay community to HIV/AIDS occurred in the context of a history of discrimination. Gay men held a similar mistrust of authorities. Furthermore, this history framed not only how gay men reacted to the threat of HIV/AIDS, but also how the mainstream community came to perceive the virus. Despite global epidemiology now demonstrating it to be overwhelmingly a pandemic affecting heterosexual people, in Australia in the early 1980s (and arguably still) HIV/AIDS was very much perceived to be a ‘gay disease’. Negative attitudes toward gay men turned HIV/AIDS into a stigmatised disease, one associated with immorality and deviant behaviour. In other words, the physiology of a disease is by no means the only factor that shapes how people perceive, and react to, it.

This chapter explores the history of homosexuality in Australia, including the changing political and social environment leading up to the 1980s when AIDS first appeared. This history explains the fear generated by HIV/AIDS amongst the gay community, not only of the disease itself but also of the potential social and political ramifications brought about by the emergence of a contagious disease that was directly associated with gay men. Australia’s history of homosexual discrimination
meant that when HIV/AIDS first emerged the gay community greatly feared that it would lead to a significant reduction in civil rights and freedoms for gay men and lesbians. The AIDS movement mobilised to protect these rights.

**Sodom of the South: Gay Australia Since 1788**

Homosexuality, often primarily defined and conceptualised by the act of sodomy, has been part of public consciousness in Australia since the early settlement. The first Governor of the Australian colony established in 1788, Captain Arthur Phillip, is recorded as saying:

> There are two crimes that could merit death – murder and sodomy. For either crimes I would wish to confine the criminal till an opportunity offered of delivering him as a prisoner to the natives of New Zealand, and let them eat him (Captain Arthur Phillip, quoted in (French, 1993:5).

There is minimal documented evidence of homosexual activity in the very early days of Australian settlement. This, of course, does not necessarily mean that it was a rare occurrence. Rather, it is more likely that the threat of severe punishment ensured any sexual act between two men remained extremely covert. Social conditions in the settlement, and later on in the predominantly male frontier, suggest that sex between men was probably fairly common. As Lewis points out: “From what is known about situational homosexuality in modern prisons, the bringing together of large groups of males in barracks and prisons must *prima facie* have promoted homosexual activity” (Lewis, 1998:429). Some commentators point out that by the early 1800s Australia had developed a reputation of being the ‘Sodom of the South’, an image articulated
in the testimonies of Roman Catholic clergyman, Dr William Ullathorne, Vicar-General in the colonies at the time. In his report on the state of the Catholic mission in Australia, for the *Cardinal Prefect of Propaganda Fide*, Ullathorne provided considerable detail of the existence of a “class of crime ... which St Paul, in detailing the vices of the heathens, has not contemplated” (cited in Fogarty, 1992:63).

Similarly, the 1837-38 Molesworth Committee on (convict) Transportation heard evidence from Superintendent James Mudie that homosexuality at the Sydney Cove Settlement was far from uncommon (Stannard and Murphy, 1989:50; Simes, 1992:31). Mudie stated that: “Upwards of 150 male couples may be pointed out who habitually associate for this most detestable intercourse, whose moral perception is so completely absorbed that they are said to be ‘married,’ to be husband and wife...” (cited in Stannard and Murphy, 1989:50).

Sodomy was an offence punishable by death in the early Australian colonies, the first hanging taking place when a man named Alexander Brown was committed to die for engaging in sex with another man. Despite all evidence suggesting that Brown’s sexual partner was willing (the partner’s death sentence was commuted), the hanging went ahead in 1828. The last execution in Australia for the charge of sodomy took place in Tasmania in 1863, capital punishment for homosexual sex ceasing when the 1885 (British) Criminal Amendment Act was introduced. This act made all male homosexual acts (including mutual masturbation) a criminal offence,

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19 The intention of ‘anti-sodomy’ laws seems to have been to prevent homosexual sex rather than sodomy itself as acts of sodomy within heterosexual relationships are very rarely mentioned within the context of anti-sodomy legislation.
but deemed the maximum punishment to be life imprisonment rather than death (French, 1993:7; Lewis, 1998:429).

In its first period of settlement, Sydney would not have been large enough to allow the anonymity which made possible the extensive gay subcultures that existed in London and other major cities at the time. There was, however, evidence of a few gay ‘beats’ in Sydney in the early decades of the 1900s, and by the 1920s there was an emerging gay underground in all major Australian cities (Lewis, 1998:429; French, 1993:43-45). Publicly, however, there was a veil of silence around homosexuality and Australian social attitudes tended to be fairly conservative through the first half of the twentieth century (Lewis, 1998:429). There are numerous reports from this time of police raids on gay and lesbian gatherings. For example, in 1942, five men were arrested in a raid on a house party in Annandale, Sydney. Four of them appeared in court the following day still dressed in drag (French, 1993:85-86). The press in Australia throughout the 1940s began to promote the idea that an increase in the number of men appearing in court for homosexual-related offences was indicative of a growing culture of ‘sex perverts’ in Sydney. Various organisations began to respond to this. The Country Women’s Association, for instance, held a conference in 1949 which resolved to urge the government to implement heavier penalties for (homosexual) sex crimes (Lewis, 1998:430).

Despite this, there were some indications that social and sexual conventions were becoming more relaxed during the post-WWII period, and gay sub cultures had began to grow. For instance, in 1949 an article appeared in a Sydney newspaper The Sun documenting the workings of the Sydney gay scene. The article discussed the
lives of gay men without the usual references to perversion and sex crime, a rarity in mainstream media and possibly a sign of changing attitudes (French, 1993:89).

This was short-lived, however, as the cold war atmosphere of the 1950s ushered in a new climate of intolerance towards any signs of non-conformism or radicalism. All things considered morally or politically 'deviant' were a target of suspicion and sanction, and communism and homosexuality were often seen to be associated. For example, a number of media reports in the 1950s raised concerns about homosexuals working within the government bureaucracy. This was considered to be a problem because homosexuals' loyalty to the government and nation was thought to be questionable. In the early 1950s, the Australian media reported on a British Medical Association report that had concluded homosexual men were more likely to be faithful to each other than to their country (French, 1993:99). The media also reported widely on efforts in the US and Britain to 'weed out' homosexuals from government jobs. For example, an article published by the Truth in April 1950 discussed a crackdown on lesbians and homosexual men employed by the United States Federal Government in which 91 people were forced to resign following investigations into their personal life. This purge was explained on the basis that gay people were considered a security risk: 'perverts' being assumed to be more likely to commit espionage (French, 1993:100). While, unlike the US, homosexuals were never banned from Australian government jobs, in the early 1960s Prime Minister Menzies directed that no homosexual would be allowed access to classified information (French, 1993:100).
The 1950s also bore witness to increasing media concern with ‘moral indecency’. In November 1951, Church leaders and judges broadcast on ABC radio a “Call to the People of Australia”. This announcement aired concerns about the moral decay of Australia. It was accompanied by media reports such as one in the *Sydney Morning Herald* in October 1951 in which New South Wales Police Superintendent Colin Delaney spoke of an ‘alarming’ increase in male homosexuality (French, 1993:89; Lewis 1988: 431). Media reporting frequently exaggerated the rate and nature of homosexual acts. For example, following a series of arrests at a gay party in Newcastle in June 1952, the media sensationalised the issue making claims such as: “A society of perverts, membership of which was quite large, existed in Newcastle” (cited in French, 1993:90). Police attention began to focus much more closely on homosexual ‘crimes’ leading to a large number of arrests. In total, the number of people convicted of ‘unnatural offences’ in Australia between 1945 and 1960 exceeded 3000. In many states special ‘vice-squads’ were formed specifically to target “parks and lavatories frequented by perverts and prowlers” (Willett 2000: 10-11).

In 1958, the subject of homosexuality first appeared in the *Sydney Morning Herald Quarterly Index* signaling the beginning of more regular coverage in mainstream ‘broadsheet’ press. Prior to this ‘moral indecency’ had largely been an interest of the tabloids only (French, 1993:99). This was probably a sign that concerns about homosexuality had reached a higher, more mainstream, profile as appearance in the less sensationalist media certainly did not mean that articles were more balanced or tolerant of homosexuality. As Robert French comments, reporting in the ‘quality press’, “far from being the dawn of a new enlightenment, simply reiterated all the old
prejudices of a British colonial society, spiced with a dash of American witch-hunt mentality" (French, 1993:99). Despite this, broadsheet papers tended to attract a less conservative readership than the tabloids and the letters pages in the Sydney Morning Herald sometimes indicated a more liberal public view than that which was reported by journalists. For example, in response to an article printed in 1958 in which NSW Police Commissioner Colin Delaney stated that homosexuals were ‘Australia’s greatest menace’, one letter writer aptly pointed out that: “The great increase in convictions is due not to any natural increase in homosexuality but to the increased zeal of the police in obtaining offences” (cited in French, 1993:99).

It is difficult to assess conclusively where public attitudes toward homosexuality stood during this period. It wasn’t a topic of academic concern and the first public opinion polls on the issue weren’t conducted until the late 1960s (Reynolds, 2002:11). However, it is reasonable to assume that few people (knowingly) had contact with, or knowledge of, gay men or lesbians beyond what was reported in the mainstream press, putting the media in a powerful position to influence public perceptions. If the average heterosexual Australian relied on 1950s media reporting alone to gain an understanding of homosexuality, their perception would have been one of crime and perversion, and a lifestyle dedicated to cross-dressing and sex in public parks.

The 1960s, however, saw a new profile emerging as the medical and psychological professions began to take an increasing interest in homosexuality. The Kinsey reports in the late 1940s and early 1950s had been among the first of a number of new studies into human sexuality. In the 1960s, ‘sexology’ as a discipline began to
range of psychological disorders including homosexuality. The treatment involved
electroshocks and other forms of aversion therapy (Reynolds, 2002:13).

This new medicalised definition became more common in public discourse,
normalising the idea that homosexuality could be viewed as something other than
criminal, or deliberately perverted, behaviour. Harsh policing and punishment of
homosexual sex came to be less tolerated (Reynolds, 2002:18). However, the
underlying message of both the medical and criminal models of homosexuality was
that gay men and lesbians required surveillance. The medical model positioned
homosexuality as a condition or illness that needed to be diagnosed, and possibly
cured, by professional intervention. This allowed the medical professions to overtake
the state as the authority with the legitimate right to manage and control homosexual
lives. Medicalisation did not create room for a positive or even a self-determined
image of gay men and lesbians. As Reynolds writes: “By the very nature of their
neurotic condition, homosexuals were denied an autonomous sexual existence –
exerts represented homosexuality and their official prognosis neatly encapsulated
the constraints of a medical discourse” (Reynolds, 2002:20). It was not until 1974
that the American Psychiatric Association removed homosexuality from its
(internationally recognised) diagnostic list of mental disorders (Thompson, 1985:95).

Pushing for Law Reform – the 1960s onward

The 1960s saw major changes in general social attitudes toward sex and sexuality.
The ‘counter-cultural’ movement was strong and sexual liberation was the catch-cry
of the decade. As Miller describes, “The hippies were the vanguard of a
revolutionary smashing of sexual taboos” (Miller, 1991:55). Although the movement
for gay liberation didn’t emerge directly from the counter culture ‘revolution’, it certainly created an environment where homosexuality was more acceptable and there was heightened political and public support for gay law reform in western countries (Miller, 1991:56). However, unlike the United States and Britain where demands for decriminalisation came from a radicalising gay movement, the early push for law reform in Australia came from welfare organisations and churches who argued that gay people were in need of treatment and support rather than criminal sanction. That is, calls for decriminalisation began to emerge in Australia on the back of the medicalisation of homosexuality not more liberal attitudes. In the 1960s, Reverend Ted Noffs of the Wayside Chapel in Kings Cross, Sydney, urged the State Government to consider law reform so that homosexuals could seek ‘treatment’ without fear of arrest. Similar calls were made by a committee of inquiry established by the Presbyterian Church in 1967 (Lewis, 1998:432).

Australia has not been subject to the fundamentalist zeal and political might of the far right religious groups that dominate the social agenda in the United States. However, religious leaders tend to be considered legitimate commentators on matters of human sexuality and they have a strong presence in public discourse on this issue. The media regularly consults and quotes church leaders on matters relating to sexuality and relationships. Since the 1970s, several non-Catholic church groups in Australia, including the Religious Society of Friends (the Quakers) and the Uniting Church, had been in favour of law reform to decriminalise homosexuality. The South Australian Methodist Church also endorsed law reform at their 1972 conference, and the social questions committee of the Melbourne Anglican Diocese in 1971 stated that homosexual acts need not be considered criminal even though they do not
accord with Christian values (Lewis, 1998:437). However, the Christian approach, while promoting tolerance, still maintained the line that homosexuals needed ‘help’. The New South Wales Presbyterian Assembly, for example, expressed their support for law reform while also appealing to the State Government for funds to research the causes and cure of homosexuality (Reynolds, 2002:22). This approach, based on the medical model, didn’t afford any autonomy to gay men and lesbians. Homosexuals were considered to be people who needed care, and the church played the role of advocating their needs as perceived through religious values (Reynolds, 2002:22).

The notable exceptions to the ‘compassionate’ approach taken by Australian churches were the Sydney Archdiocese of the Anglican Church and the multi-denominational conservative grouping, the Festival of Light (FOL). Along with the official voice of the Catholic Church, these both represented long-time vocal opposition to homosexuality in Australia. A Sydney Anglican Archdiocese report on homosexuality in 1973 stated that homosexual sex should remain criminalised as it threatened the institution of marriage and was ‘intrinsically wrong’. To this day, these groups tend to receive regular media coverage and are generally consulted by journalists on their views regarding sexuality – if only as a source of controversy to spice up media stories. However, while it attracts a following in some areas, extreme religious conservatism is often depicted in Australia as irrational or ‘loopy’, particularly the antics of FOL spokesperson, Reverend Fred Nile. As such, they have not had the same impact as the far-right churches in other countries, particularly the USA. In Australia, those churches calling for decriminalisation of homosexuality probably had greater political influence (Lewis, 1998:438).
The first political lobby group dedicated specifically to gay law reform, The Homosexual Law Reform Society of the Australian Capital Territory, was formed in 1969 after two men were arrested for engaging in homosexual practices when they were found in a parked car on the outskirts of Canberra (Lewis, 1998:432). This group was comprised of academics, lawyers and civil libertarians, some of whom were gay but certainly not all. Support for law reform also came from individual Members of Parliament. For example, in 1967 Bill Hayden, who would later become Leader of the Federal Opposition and Governor General, suggested establishing a national committee on gay law reform and looked at ways the Federal Government could override the states on this issue (Lewis, 1998:432).

Don Dunstan, the Attorney General and popular leader of the South Australian Labor Party, had been pushing for law reform in that state since the mid-1960s. When he became Premier in 1970 the campaign reached new ground and South Australia became the first Australian state to decriminalise homosexuality in 1972 (Bull et al., 1991:2; Willett 2000:92-93). The Federal House of Representatives followed suit in October 1973, voting 60 to 44 in favour of a motion to decriminalise homosexual acts. It was not until 1975, however, that draft law reform was sent to the Attorney General so legislation could be amended in the Federal Territories (Lewis, 1998:232 and 433). In the ACT, homosexuality became legal in 1976, although the law was not put in place in the Northern Territory until 1983 (Bull et al., 1991). In 1978, the Commonwealth Royal Commission on Human Relationships concluded that it was ‘unnecessary’ to put homosexuality on the criminal code and that it should only be an offence in the case of rape or where it offended public decency and order (Lewis,

In July 1982, the NSW anti-discrimination commission released a report which made 35 recommendations including: decriminalisation of homosexuality; better education within schools about homosexuality; and, improving relations between gay people and the police force, beginning by ending the common police practice of surveillance and deliberate trapping of homosexuals. The report received publicity in all major newspapers but was ignored by the state government (see Mercer, 1982: 2; Canberra Times, 1982: 6; The Age, 1982: 5; Cumming, 1982: 3). NSW repealed laws criminalising homosexuality two years later in 1984 (Bull et al., 1991:2).

The push for law reform came much later in Queensland and Western Australia, 1990 and 1989 respectively\(^{20}\), and when it did come it wasn’t necessarily indicative of more progressive social attitudes among politicians. For example, when the new laws were introduced in Western Australia (the 1989 Law Reform, Decriminalisation

\(^{20}\)The relatively late change in law in Western Australia, Tasmania and Queensland also meant that in the mid 1980s Australia was one of only three other Western democracies (alongside Ireland, a number of states in the United States and Israel) to maintain consensual adult homosexual sex as a crime (Altman, 1989:49). Paradoxically, however, a few years later Australia also led the way in the area of anti-discrimination law. In NSW and South Australia there were legal protections from discrimination on the grounds of homosexuality in place by the end of the 1980s (Altman, 1989:49).
of Sodomy, Act), state parliamentarians insisted on inserting a preamble to the legislation which, while acknowledging that they felt it to be inappropriate for criminal law to intrude on personal sexual relationships, expressed their overt condemnation of homosexuality (Bull et al., 1991:2). Furthermore, while male-to-male sex was made legal, a range of new offences prohibiting the ‘encouragement’ or promotion of homosexual behaviour were introduced. This included a section on the illegality of ‘promoting’ or ‘encouraging’ homosexuality within educational institutions (Pereira, 1999).

Homosexual law reform was also limited to the notion of ‘actions undertaken in private’. While this was probably considered to be the most acceptable, or at least less controversial, way to approach the debate it had the effect of containing the laws – maintaining only limited acceptance of homosexuality. Public displays of homosexuality could still be considered indecent or offensive in a legal sense (Reynolds, 2002:29). Nevertheless, the debate over law reform did open space for public discussion on homosexuality that was not immediately associated with criminality, illness, sinfulness or immorality. Ideas of human rights and minority representation began to carve out a new frame for the public treatment of gay men and lesbians (Reynolds, 2002:29).

**Public Opinion**

The first Australian survey of public attitudes toward homosexuality was conducted by criminologists in 1968, with the results published in the *Australian Law Journal*. The survey indicated that only 22 per cent of respondents favored homosexual law reform and many felt that punishment for engaging in homosexual acts should be
"severe whipping" or "a long period of imprisonment" (Reynolds, 2002:11). However, when the same survey was repeated in 1971 more than half of respondents (56 per cent) indicated their support for law reform (de Waal et al., 1994:2). In 1965, an article was published in the Bulletin by criminologist Gordon Hawkins discussing myths and stereotypes about homosexuality and changing public attitudes toward law reform in the UK and America (Lewis, 1998:431). Hawkins was, at the time, one of the few high profile authors seriously bringing homosexuality to public attention and he was able to gain a sense of attitudes through peoples reaction to his publications. In 1970, Hawkins expressed optimism for law reform, commenting on what he observed to be a marked increase in positive public attitudes toward homosexuality (Reynolds, 2002:11).

In 1973, Australian National Opinion Polls asked people what their reaction would be if they found out two men were living together in a relationship in their neighborhood. Of the respondents, 8 per cent said they would inform authorities or police and 75 per cent said they would consider it none of their business (de Waal et al., 1994:3). In 1974, a Morgan poll indicated that just over half of all respondents (54 per cent) thought sexual acts in private between consenting males should be legal (de Waal et al., 1994:3). However, while polls tended to indicate public support for decriminalisation and non-intervention into gay relationships, there was still a view that homosexuality was morally wrong. For example, the 1984 Social Science Survey Australia found that 64 per cent of respondents indicated that they believe homosexual behaviour is always wrong. In the 1999/2000 survey 48 per cent of respondent felt it was always wrong (Kelley, 2001:16).
Simon Watney once wrote that “a specific cultural agenda imposes its values via the very questions it asks”. While opinion polls tend to be inconsistent and are unlikely to be the most reliable reflection of broad public opinion, the fact that such polls exist on the issue of homosexuality is in itself indicative of a belief that homosexuality is a ‘public issue’ in a way that heterosexuality is not (Watney, 1994:25). The history of regulation of homosexuality, whether medical or legal, has positioned it as a political and social ‘problem’ considered to be a valid topic for public debate. There is a sense that society and the state, rather than individuals, have a right to decide if homosexuality is acceptable behaviour or not and sanction it accordingly. Similar debates rarely, if ever, occur on the topic of adult heterosexuality.

The history of homosexuality is one marked by professional intervention into the lives of gay men and lesbians. While homosexuality had been subject to much public debate, it was generally a debate played out in the media between medical and legal ‘experts’. Gay men or lesbians had no voice in such discussion. Indeed, the construction of homosexuality as either ‘illness’ or ‘crime’ meant gay men and lesbians were, on the whole, deliberately excluded from communicating their opinion. It was only with the emergence of organised gay and lesbian activism that this began to change.

The Gay Movement in Australia

Unlike America, Australia did not have long-established gay and lesbian political organisations, such as the Mattachine Society and other groups associated with the early (1950s) ‘homophile’ movement. Australia also did not have the same radical
edge to gay activism that had existed in the US since the infamous Stonewall riots that took place in New York in 1969 (Thompson, 1985:9-10). However, by the end of the 1970s there was a fledgling gay and lesbian movement in Australia and a number groups were forming around the issue of gay law reform, the largest being Sydney-based group Campaign Against Moral Persecution (CAMP).

According the Graham Willett: “If the Australian lesbian and gay movement can be said to have a birthday, 19 September 1970 is it (2000: 33)”. It was on this day that a feature article published in the *Australian* newspaper announced the formation of CAMP. Two friends, John Ware and Christabel Poll, conceived the idea for CAMP over a bottle of whiskey. It was to be one of the first overtly political, gay organisations in Australia. Prior to this, gay and lesbian groups had generally been social or support based and non-political. However, it seems that in the 1970s the time was ripe for a shift to a more political orientation as year after the feature on CAMP appeared in the *Australian*, the group had acquired over 1500 members. What began as a loosely structured collaboration developed into an established organisation with set procedures and a constitution (Thompson, 1985:11).

Encouraging gay people to ‘come out’ publicly was a core tactic of CAMP in the early 1970s and this resulted in some high profile publicity in Australian newspapers and a growing membership of the organisation (Thompson, 1985:12-13).

Unquestionably it was the willingness of CAMP’s leaders to come out publicly as homosexuals that elevated CAMP from a ‘sort of book club’ to the founding organisation of a social movement. Never before had anyone in
Australia willingly identified, indeed proclaimed, themselves as homosexual to the media as Ware and Poll were doing. Their courage was the spark that lit the bushfire (Willett 2000:39).

CAMP first shifted its attention from publicity stunts to collective protest in October 1971, when they demonstrated outside the Liberal Party headquarters during pre-selection for the seat of Berowra in NSW. Berowra’s sitting member, Tom Hughes, a man who had demonstrated cautious, but relatively progressive support for gay law reform was facing a conservative challenge from a contender known for his homophobic views, Jim Cameron (Thompson, 1985:15). The protest had not been easy for CAMP to organise as fears of attracting anti-gay violence meant that the time and place were advertised only by word-of-mouth. However, the crowd that turned up was fairly large and certainly vocal. They carried banners proclaiming that ‘Cameron hates homos, but he’ll sure b-g-r the Liberal Party’, and handed out leaflets explaining CAMP’s position to delegates as they entered the meeting (Willett 2000: 49).

While Tom Hughes easily won the pre-selection and the demonstration was deemed a success, CAMP did not continue to grow as a ‘radical’ organisation. Inhibited by the lack of any precedent in Australia for more radical gay action, major legislative or political change was not on CAMP’s agenda – particularly in branches of CAMP outside of Sydney. Instead the organisation tended toward conciliatory statements aimed at convincing the broader public that gay men and women were just average people (Thompson, 1985:15).
Australian gay activism began to focus more directly on political change from the mid-1970s, when people began to mobilise around the issue of law reform. In 1975, the Australian Union of Students (AUS) adopted a pro-gay policy and sponsored the first annual National Conference of Lesbians and Homosexuals (Ballard, 1992:137). The AUS engaged in a campaign to reduce homophobia on campuses, and within teaching practices. They also mounted a major public defence of Queensland teacher Greg Weir who had been refused employment as a teacher on the basis of his homosexuality (Willett 2000: 123). From this, an action group called Melbourne’s Gay Teacher’s Group was formed, leading to an ongoing campaign to ensure job security for gay and lesbian teachers (Willett 2000: 125). Actions such as this began to draw attention to the legal status of homosexuality and the lack of legal protections in society for gay men and lesbians. By the end of the 1970s there was more consistent political organising occurring around the issue of the decriminalisation of homosexuality.

Gay and lesbian activism in Australia achieved perhaps its highest public profile with the event now marked as the first Sydney Gay and Lesbian Mardi Gras. On 24 June 1978 a group of protestors marched down Oxford Street in Sydney. The march was held to commemorate the Stonewall riots that had begun on the same date in 1969, following the raid on a gay bar in Greenwich Village. The protest was also intended to draw attention to the ongoing campaign for law reform in Australia. Marching down Oxford Street, demonstrators hoped people would be drawn out of bars and pubs to join them. The protest was peaceful and had been given all necessary approval by authorities. However, as they reached the end of Oxford Street, police unexpectedly attempted to disperse the crowd. Protestors reacted
angrily to this, leading to a violent confrontation. This continued for some time and a number of protestors were arrested. Allegations of police brutality soon followed (Ariss, 1997:26). Eventually, those demonstrators who had not been arrested held a frantic meeting back at Paddington Town Hall at which bail was raised to release those now held by the police (although the amount was only $70-$100 for each person, it required a fair amount of organisation to gather the cash late on a Sunday afternoon in pre-ATM-machine 1978). The meeting also devised a media communications strategy and influential people within the gay community were contacted and mobilised. The demonstrators re-gathered outside the police holding cells until protestors were released (Carswell 2006)\textsuperscript{21}.

The following year, June 1979, another protest march was assembled in commemoration of the violent events of the year before. This march was not prevented by police and it went ahead, peacefully, as planned. The event became an annual gathering, growing over the years to become one of the largest street festivals in the world, the Sydney Gay and Lesbian Mardi Gras Parade. In 1983, six years after the first protest, twenty-thousand people attended the parade – which by this stage had been moved from June to March to catch the end of the Australian summer. By 1994, the number of ‘Mardi Gras’ spectators had increased to four-hundred thousand. In addition, Mardi Gras had become a month long community festival incorporating arts and sporting events (Lewis, 1998:437). While there is debate about whether or not the Sydney Gay and Lesbian Mardi Gras should be considered a ‘social movement’ or even a political initiative, there is no doubt that

\textsuperscript{21} Phil Carswell, personal communication with the author on 25 October 2006.
the annual event created unprecedented publicity for the Australian community of gay men and lesbians (Marsh and Galbraith, 1995: 301). As Dennis Altman has observed:

Of course, now [Mardi Gras has] become a massive event that is recognised by almost everybody as part of – as one of the things that happens in Australia in Summer: certainly, in Sydney ... [For] example, the last Mardi Gras the Sydney Morning Herald had a special Mardi Gras crossword that Saturday. Now, this is the newspaper which 20 years ago refused to use the word 'gay' in its pages. That change, I think, is symbolic of what's happened, which is, that the lesbian and gay community, which is now the term which is most often used, has actually become recognised as a legitimate community in Australian life – most obviously in Sydney, but to a considerable extent elsewhere. We see that reflected in politics. It was very clear in the last election when politicians were courting the votes of that community (Altman, 1993)\(^22\).

Although 'Mardi Gras' had become a major focus of gay and lesbian activism, in the early 1980s homosexuality still remained on the criminal code in most Australian states and a number of organisations were being formed separate to Mardi Gras to tackle this issue. In Sydney, two gay activists, Lex Watson and Craig Johnston (both of whom would later go on to be involved in AIDS activism), established the Gay

\(^{22}\) Dennis Altman interviewed by Heather Rusden 7 July 1993, for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC 2815/37
Rights Lobby (GRL), its first meeting being held in February 1981. The GRL began a campaign involving lobbying, petitioning, media liaison and community education around the law reform issue. They also sought support from churches and other community groups. In late 1981, GRL mounted a campaign around the state election, lobbying candidates and voters in key seats. The organisation found support for their goals from a left-wing member of the NSW parliament, George Petersen, when he announced his intention to try to repeal laws that criminalised homosexuality. The GRL worked closely with Petersen to draft his bill. They also continued to campaign among the gay community, generating enthusiasm for the prospect that law reform could become a reality. When the bill was to be tabled in April 1981, 500 people attended a demonstration outside the NSW parliament. Although Petersen’s bill was defeated and the laws remained unchanged, these actions still represented a surge in momentum for activism around gay law reform (Willett 2000: 159-160).

The issue resurfaced in January 1983 when police raided a gay nightclub in Sydney’s inner suburbs. During the raid over 100 men were detained and four people were charged with indecent assault. Police claimed that they had only visited the club following a complaint made by a patron. But once there, they had apprehended a number of men, taking their names and, in some cases, the contact details of their employers (Coultan 1983: 3; Sydney Morning Herald 1983: 10; Border Morning Mail 1983: 8). At the time, under the crimes act, a man charged with indecent assault against another man (sodomy) could be sentenced to 14 years gaol in NSW and consent could not be used as a defence (this was despite the charge of ‘rape without violence’ attracting only a seven year sentence). Over 1000 people demonstrated at Sydney Town Hall in angry protest of the raid. The GRL released a media statement
that said: “It is ironic that at the same time police are complaining about a lack of resources and overtime that 15 officers, four cars and two vans could be devoted to harassing homosexuals” (cited in Coulitan 1983: 3). Despite this protest, a second police raid on the same nightclub was conducted less than one month later. This time 11 men were charged, some under the archaic common law offence of ‘scandalous conduct’. A second protest rally was organised, at which around 300 people demonstrated outside Sydney Police headquarters (Mercer 1983: 3; Border Morning Mail 1983: 8). Actions continued with 28 men presenting themselves to the Darlinghurst Police Station in Sydney in October 1983 with statutory declarations confessing to engaging in sodomy (Willett 2000: 163). In 1984, NSW Premier Neville Wran finally announced that he would support a bill to decriminalise homosexual sex – although not to equalise the age of consent between homosexual acts and heterosexual sex (Willett 2000: 164) 23.

Community, Identity and Activism

Although law reform had involved many hundreds of gay men, the late 1970s had also produced increasing visibility of the non-political gay scene. People now spoke about the ‘gay community’ rather than gay activism or a gay movement. There were a number of prominent non-political groups as well as a range of gay businesses including bars, pubs and nightclubs starting up in known ‘gay areas’ of the major

23 According to Dennis Altman it was only NSW that could claim law reform had been the result of movement action. Altman argues that in NSW continued pressure from activists caused enough embarrassment for the state Premier, Neville Wran, to push for conservatives within his party to allow law reform. In contrast, Victoria had no real mass gay movement. If law reform had been influenced by the work of activists, it was due to the more formal lobbying efforts of the Gay Legal Rights Coalition (Altman 1989:49).
cities (Dowsett, 1998:175). There is much debate among gay activists and in academic writing on the notion of community and whether a ‘gay community’ exists at all. Those who support the notion argue that gay men and lesbians share a community-like connection through shared social experiences, close friendship ties and strong social networks. The counter argument to this, however, asserts that similar experiences of sexuality do not create a basis for community and that the lives of lesbians and gay men are too diverse to warrant the term ‘community’ based on common social identity. There is also a concern that the growth of a gay ‘community’ represents the de-politicisation and increasing commercialism of gay identity. In this approach, gay community is seen to amount to the ghettoisation or containment of gay politics (Ariss, 1997:27). However, in the early 1980s there was a sense of politics and activism present in the general gay community that reflected a collective consciousness of the marginalised status of gay men and lesbians and their history of activism. For example, the two major gay community publications at the time had overtly political titles, Campaign, published in Sydney since 1975, and Outrage published in Melbourne from April 1983 (Carr, 1998). The history of (and ongoing) discrimination against gay men and lesbians also meant community events such as the Sydney Gay and Lesbian Mardi Gras festival were grounded in a sense of politics in a way that mainstream festivals are not (Lewis and Ross, 1995:38). As Ariss writes: “While not all gays participating in the Mardi Gras may consciously perceive it as a political event, participation is a very emotionally charged experience, much like a religious ritual” (Ariss, 1997:28). Moreover, Ariss argues, the concept of gay community in itself has political utility.

24 The immediate precursor to Outrage was a publication called Gay Community News.
Gay identity was now socialised via this link to a “community” of like others. “Gay” constituted a quasi-ethnic identity with geographical, social, behavioral, and cultural features shared by its members. By socialising gay identity, political strategies were opened up to include more diverse forms of activities and greater participation in terms of numbers of people involved (Ariss, 1997:28).

The fact that there was an existing gay and lesbian media and a history of organised activism among the gay and lesbian community, meant that when AIDS first arrived in the early 1980s gay men were in a strong position to respond to it collectively. 25 Organisational structures necessary for political mobilisation were, to a large extent, already in place. Movement constituents were also drawn from people who identified personally and socially with the visible gay community, even if they did not consider themselves to be politically engaged.

[In] the gay community there was a capacity to behave in an organised, political way because if you consider the timing of when HIV came along, it came along at a time when the gay community (gay male community, although there was a lesbian community it wasn’t ever as illegalised nor at the time as organised) ... so the gay boys were fighting for political rights, they were out and about and outspoken, they were forming organisations. So

25 This point has been made by several authors writing on the Australian response to AIDS (see, for example, Altman 1988, Ballard 1989, Misztal 1991, Sendziuk 2003).
we’re talking about a group who were skilled, articulate and organised. And on that foundation came HIV ... [In] Melbourne they had gone down the path of developing an organisation called ALSO [Alternative Life-Styles Organisation]. At the time that HIV came along ALSO had been raising funds in order to establish a gay and lesbian retirement village, or some sort of aged care facility. That money got diverted into the AIDS Council to put up a mechanism to respond to AIDS. In Sydney, the people who had been involved in the gay rights movement immediately became the people who were involved in HIV. So politically what drove people to action was the fact that they had a nascent community, and incredible amount of political will and intellect drawn into that and they saw that they stood to lose everything if they didn’t act. There was a potential there to lose any of the benefits (Crooks, 2005)26.

The ‘Homosexual Cancer’: AIDS = Gay

Reports about a lethal mystery disease began trickling into mainstream Australian media by mid-1982, some months before the first Australian case would be diagnosed. The reports told of an increasing number of unexplainable cases of Karposi’s sarcoma and pneumocystis pneumonia (PCP) among young gay men in America. Both these illnesses are relatively rare and indicative of problems with the body’s immune system. What doctors couldn’t explain was why so many previously healthy, young men were presenting with damaged immune systems. They also

26 Levinia Crooks interviewed by the author on 28 January 2005.
couldn’t explain why nearly all these young men seemed to be gay (Kraft, 1982: 6; Chadwick, 1982: 16).

Before HIV was identified as the virus leading to AIDS, a number of theories pointed to a causal link between homosexuality and AIDS. For example, the ‘overload theory’ suggested that the gay lifestyle, including a combination of drug use, poor health and a history of sexually transmitted infections, led to a collapsed immune system (Seidman, 2002:377). Similarly, a report in the Launceston Examiner in 1982 explained that researchers were “studying the effects of drugs used by homosexuals to enhance orgasm, and have examined the possibility that frequent bouts of venereal disease among homosexuals might break down the body’s ability to fight illness” (Kraft, 1982:6). In the absence of any information beyond an observed link between immune system problems and gay men, researchers began using the term “GRID” (Gay Related Immune Deficiency) to describe the appearance of Karposi’s sarcoma and other infections among this population group. The media followed suit, coining a number of terms including ‘the homosexual cancer’ and ‘the gay plague’ (Seidman, 2002:377; Watney, 1994:51). Even when the clinical diagnosis of HIV was made, and people became aware that the virus could also be spread through heterosexual sex, the perception that there is an intrinsic link between homosexuality and AIDS has tended to persevere in western countries.

The basic known facts about AIDS in the early 1980s, before HIV was discovered, were that it was contagious and deadly. This merged with existing homophobic attitudes to produce an image of gay men as diseased and dangerous: guilty not only of misdirected sexual predilections but of their newfound potential to infect and kill
‘normal’ Australians. All gay men came to be seen as potentially contagious and deadly. As Gary Dowsett has written: “It is almost as if gay men were the virus and that they, rather than it, caused the pandemic” (Dowsett, 1998:173). Steven Seidman agrees, arguing that the response to HIV/AIDS in western society was structured by homophobia.

AIDS has contributed to reviving the notion of the homosexual as a dangerous and polluted figure. Moreover, the revitalization of a discredited image of homosexuality structured the public response to AIDS. As a principle victim of AIDS but also identified as its chief perpetrator, homosexual men were doubly victimized: by the disease and by society’s response to it (Seidman, 2002:379).

All diseases, particularly those that are contagious, lend themselves to some degree of moral interpretation: leprosy, for example, has long been associated with poverty and lack of hygiene and syphilis has been linked to prostitution, adultery and other behaviour considered ‘immoral’ (Pereira, 1999). It is not difficult to understand how AIDS brought with it the potential to create a new social foothold for homophobia and why people feared it could become the basis of renewed calls for the punishment of homosexuality (Pereira, 1999). From the outset, AIDS was directly associated with a sexuality and lifestyle already subject to social stigma, disapproval and, in many places, illegality.

In October 1989, The Bulletin magazine published a cover story on homosexuality, discussing increasing reports of acts of discrimination against gay men and lesbians
in the wake of AIDS. The article observed that the new awareness and tolerance of homosexuality had been developing since the 1960s was giving way to increasing reports of anti-homosexual violence in the major Australian cities:

Public ignorance associated with AIDS is believed to have had much to do with the slide back into the fear and loathing of the 50s when all queers, poofers and dykes were regarded as fair game (Stannard and Murphy, 1989:50).

There is some evidence to support this statement. For instance, in 1985, the two major Australian airlines Ansett and TAA imposed a ban on all HIV positive passengers. Although short-lived, the ban came alongside increased complaints of workplace harassment and fears that gay men could be banned from jobs in the service industries. There were also increasing reports of gay-bashings in major cities and indications that the public supported compulsory detainment of gay men (Wilson et al., 1986:4; Synnott, 1985: 5; Mark, 1993). A survey conducted by the National Centre for Epidemiology and Population Health in 1991 found respondents felt more sympathy for people who kill themselves through drinking or smoking than for gay men who die from AIDS (Editorial, 1991: 5). By the early 1990s approximately 20 per cent of complaints regarding homosexual discrimination put to the NSW Anti-Discrimination Board contained some element of HIV or AIDS discrimination (NSW ADB, 1992:116).

Internationally there were reports that fear of AIDS was leading to overt acts of
discrimination against gay men and lesbians. In 1983, New York City Council
established an AIDS Discrimination Unit within the city’s Commission on Human
Rights. The Unit recorded numerous complaints from healthy gay men and lesbians
who had been fired from their jobs or thrown out of their homes on the basis of
allegedly being ‘AIDS carriers’ (Hollibaugh et al., 1988:128)\(^2\).

In a study on HIV/AIDS related discrimination in Australia, Kippax et al (1991)
found that people tended to justify their prejudice toward HIV positive people
because they assumed people with HIV/AIDS were likely to have engaged in
‘deviant’ behaviour (if not homosexual sex then illicit drug use). The study’s report
states that: “Even if deviance is not a central part of people’s expressed attitudes to
people with HIV, there is a level at which it underlies all discrimination, prejudice,
and the excessive fear of HIV” (Kippax et al., 1991:28). The study found that
HIV/AIDS related discrimination could not be divorced from prejudice against risk
groups such as gay men. People with HIV/AIDS were assumed to be members of
risk groups, and individual members of risk groups were automatically associated
with HIV/AIDS, regardless of their actual HIV status. That is, all gay men were seen
as likely to be infectious. Furthermore, most people’s reactions to HIV/AIDS were
not determined by the fact that it is a fatal disease, but by its association with gay
men and drug users. The fear of being associated with these groups, and becoming

\(^2\) For a detailed discussion on homophobic and AIDS related discrimination in Britain see Davenport-
the subject of such stigma oneself, was a large part of the fear of being infected with HIV (Kippax et al., 1991:24).

Uncertainty about how far or how quickly HIV/AIDS would spread in Australia, meant that in the 1980s fear of infection remained high even as the public became more educated about the physiology of HIV transmission. A 1991 study of public knowledge, attitudes and beliefs about AIDS concluded that high levels of knowledge about HIV transmission did not reduce prejudice. The researchers concluded:

The results from the two surveys indicate that in many important areas, the community’s knowledge about the nature of AIDS transmission, treatment and risk reduction is approaching saturation level, with 95 per cent or more correctly agreeing with propositions that have been central to community AIDS education efforts … Although knowledge levels about most issues may be satisfactory, our findings also point to a disturbing level of community hysteria about AIDS (Bray and Chapman, 1991:112).

According to Bray and Chapman, the survey responses indicated a deep and often misguided concern about catching HIV/AIDS. Over half of the people interviewed believed that a policy of compulsory testing was warranted and a further five per cent believed all homosexuals should be tested (Bray and Chapman, 1991:112).

The more prejudiced members of the community believe that people living with AIDS and HIV should be placed under the control of the law and of the
state, in order to prevent the spread of ‘the plague’. Others endorse the view that there should be compulsory testing of persons from ‘risk groups’ to ensure control and the prevention of further spread ... Punishment and retribution is enacted both at an institutional level and an individual level in the refusal of treatment, gay bashing, incarceration, isolation, and avoidance of people suspected of being ‘AIDS carriers’ (Kippax et al., 1991:24).

While there were few large-scale Australian studies which looked at whether or not HIV/AIDS lead to increased discrimination against gay people, what is clear is that HIV/AIDS created an environment of fear. People were concerned about contracting AIDS, and fears were exacerbated, and shaped, by the association between AIDS and an identifiable group of people who were already marginalised and stigmatised. As Steven Mark describes it, AIDS gave homophobic discrimination “a new heightened respectability in the community”, representing “discrimination on a new level” (Mark, 1993/9). It is difficult to tell conclusively how deeply or widespread public fears about AIDS were held or the extent to which this impacted on actual cases of discrimination against gay men and lesbians. However, it is clear why gay men were fearful of discrimination and/or legal sanction as a result of AIDS.

**Homophobia, Discrimination and Fear: The Beginning of AIDS Activism**

It was this environment of uncertainty and fear, occurring within the context of the history of homosexual discrimination, that shaped AIDS activism in Australia.

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there were fears that individual acts of discrimination – gay bashing, workplace harassment, withdrawal of services and so forth – would become more frequent and more socially acceptable under the premise of avoiding AIDS. Occurring in a community with such a recent history of successful political organising, these fears were quickly harnessed into collective action.

*Discrimination was rife. So gay men were fighting on a number of fronts – for the right to have sex, for the right to work and live in the community as other people are able to do, for the right to anti-discrimination protection, a whole lot of things like that. So these were all motivators and there was a sense that a community was being built and here was something that threatened to decimate the community entirely. So they were part of motivating the gay community in Australia* (Whittaker, 2004)\(^{31}\).

Not surprisingly, AIDS mobilised the gay community like nothing else had before it. On a personal level, people feared they themselves would become infected with AIDS and wanted more information about it. But also, people wanted to protect gay communities, as activist Don Baxter describes:

*It wasn’t really a particular person I knew who became positive, it was actually a general thing that, sometime late in ’83 or early ’84, the possible ramifications started to really come home to me – or what I thought the*  

\(^{31}\) Bill Whittaker interviewed by the author 6 November 2004. This particular quotation was in response to my question about what, in Whittaker’s view, motivated the gay community to take action around AIDS.
possible ramifications could be. And I was envisioning them as being quite drastic, because it seemed to me that it heralded the potential destruction of the community altogether. I always remember thinking quite clearly that what it could do would be to destroy most of the community institutions that we had. So that while we only had a sort of a relatively – or compared to now – a relatively small gay press, it seemed to me that that was very likely to go, that quite a number of gay businesses would collapse either because their proprietors would die or a lot of their customer base might die, so therefore the advertising base for the press would go as well (Baxter, 1993).3

The following story about the early mobilisation of AIDS activists in Melbourne demonstrates the organisational capacity of the gay community combined with the fear and insecurity generated by AIDS that led people to action. It also shows the numbers of people who were involved in early AIDS activism.

I was [a member of] the ALSO [Alternative Lifestyles Organisation] Foundation. I was on there as sort of the token leftie ... So when they heard news in 1982 of this new thing happening in America, we got a health sub committee together of four people. Myself, the late Ian Dunstan, the late Chris Carter and the late Peter Knight. The four of us sat down together and said what are we going to do about this? Let's call a public meeting. What we decided to do, without any advertising, we booked the Dental Hospital in

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32 Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.
Melbourne, which was a bold move—we were a gay organisation booking a straight venue. We got a panel of doctors on stage, most of them gay, one straight, and through word-of-mouth filled the auditorium—700 people. Up to that stage, it was the largest political crowd of gay people I had ever seen in my life. I mean we had warehouse parties where we had 1000 people dancing and stuff, but it was the first time I had seen 700 people sitting down paying attention and being well behaved... It was really interesting how that word got through the party scene before it got through the gay press and through the gay political scene. The Drag Queens and the Leather Queens and the Qantas Queens all knew about it, and they knew something was going on that was going to be bad and they were all there in the audience, along with your established Left-wing gay acts. That was the irony of the night. It was an amazing cross section of people who had come there all through word of mouth. The networks already were established. That strength of community that was there was nascent—or latent. But it was still quite readily and easily tapped, and once it was tapped it was like a sleeping tiger. It wasn’t going to sit down. At that meeting, I’ll never forget it was two hours of absolute terror for me because every question we asked the doctors they said: “No we don’t know”. They said: “This is what we do know, we’ve seen guys coming and in and they’re gone like that. They’re dying within six months.” This was before we knew about HIV or AIDS. It was just like they’re getting sick, body covered in splotches, they were coughing, they were losing weight, they had night sweats, diarrhoea, they had enormous
fatigue ... So that meeting with 700 people, I’ll never forget it, a lesbian activists by the name of Alison Thorne\textsuperscript{33}, who is well known in gay history and so she should be – there was a really feeling of hopelessness through the whole room, people were thinking: “Oh my god, what’s going to happen to us we’re all going to die” – and Alison grabbed the microphone and did the classic Lenin thing, ‘what is to be done?’. She said: “Look at us. We’ve got to do something about this. I vote we have another meeting in one months time at another venue and people can volunteer to take on various organising roles”, or words to that effect. It was a stirring sort of ‘man the battlements’ (oh no she’d never say that, it was ‘staff the battlements’!) speech. It was amazing, it was the perfect line at the right time and it instantly galvanised the room. People said yes we can do this, we’ve got talented people here – we’ve got doctors, we’ve got lawyers, we’ve got policy people. So a month later we had a meeting at the Laird hotel in Melbourne, a little pub in Collingwood. Ron, the owner, bless his heart (there are so many unsung heroes in this epidemic), gave us a room for free that night. So we crammed in about 35 to 40 people, which is more than we expected. We thought after a month it would die down and people would go back to their little holes. But in that room was the most amazing cross section of people. It was like the big

\textsuperscript{33} While in this thesis I only make passing reference to the role of lesbians, there were a number of lesbian women actively involved in the AIDS movement and in the subsequent establishment of AIDS organisations. The role that lesbians and heterosexual women played in AIDS activism could the topic of an interesting thesis in itself. While, this was not a topic that could be addressed with any depth in this thesis due to time and resource constraints, it worth noting the role of lesbians as it shows that people within the gay community were motivated to take action around AIDS even if the did not feel personally at risk from the virus (lesbians were never identified as a ‘risk group’ for AIDS, even if they did become implicated to some extent in AIDS-hysteria).
meeting shrunk down. You had your drag queens, your leather-boys, your political activists, then the sort of ALSO people and people who didn’t do political things before but thought this was something they could possibly help with – like nurses and that sort of stuff. And because a lot of them were party people I knew most of them, so when they asked me to chair the meeting I got shoved into the fortuitous position of being the first Chair of the first meeting of the Organising Committee on AIDS in Victoria. And I think Sydney had a similar meeting about a month earlier – we were very close. We’d been to Mardi Gras and things together, plus I had political allies in Sydney ... So there was already stuff happening up there, so it was logical that we should do the same (Carswell, 2005b)\textsuperscript{34}.

Following early gatherings such as these, mobilisation of the gay community around AIDS began to take several forms. The very early stages of AIDS activism saw people beginning to build from the political and organisational framework that had been set up by the GRL and other groups around gay law reform, developing campaigns to defend the civil rights of gay men and lesbians. Other people focused on researching and disseminating information about AIDS to the gay community. Largely this involved sourcing as many articles as possible from US publications and reprinting, or summarising, them in the Australian gay press. There was also a large group of people who began to arrange care and support services for those who were ill with AIDS-related infections. There were indications at the time that because

\textsuperscript{34} Phil Carswell interviewed by the author on 23 July 2005. The quotation was in the context of a general discussion about Carswell’s involvement with the community AIDS response.
AIDS was emerging as a gay disease mainstream services would not respond adequately to care for people with AIDS. Hence, care and support became one of the first major areas of AIDS activism.

If you’re talking about what caused people to act from a compassionate side of it then I think two things happened. One was again, within an organised gay community, people acted philanthropically and compassionately because they were being actively discriminated against by the broader community. So for example, it should never have been the case that there was a need to develop an organisation such as CSN [Community Support Network]. It was the case, it was definitely the case, that people were dying in their homes because home care wouldn’t come and look after them. [People were] scared of catching (HIV) and that being manifest, even if they didn’t say they were scared, into hostility toward people with HIV. Yeah, a downright, flat out refusal to go and care for people! I’m talking about a time in the early ’80s where you had people in hospital in Prince Henry where nursing staff were having to feed patients, if there were nursing staff that were prepared to be working there (nursing staff numbers were quite small). Loved-ones had to come in and feed their patients because the catering staff refused to do anything but leave trays at the front steps of the ward. Now in an environment like that you have to act. It is wrong that you have to act, it is

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35 The Community Support Network (CSN) was one of the first home care and support services set up for people with AIDS. It was established at a grassroots level by people within the gay community and was entirely volunteer run. CSN still exists today. Now it has some paid staff and is linked to the AIDS Council of NSW.
wrong that you have to establish a parallel process. But there is a period of time in which you do have to do that. When I say people were acting benevolently ... if you think in the very early '80s with the first fundraising activity that was put on by a group of gay men in Sydney which was to raise money for a guy called Bobby Goldsmith so he could remain at home and die at home rather than have to be hospitalised. And we're talking about a situation where if there wasn't money made then his rent wouldn't be paid and he wouldn't have anywhere to live. So you put those sorts of things together... the reason BGF [Bobby Goldsmith Foundation] sprung up at the time was because that man could not stay at home without being assisted by a groups of peers and friends and that group, BGF, worked very closely with CSN to provide them with the necessary goods they require to keep someone at home, whether than was food supplements, commode chairs, ripple mattresses, some of that stuff you can get from hospital [but] not always was it available from the hospital (Crooks, 2005)36.

AIDS ushered in a new level of fear and uncertainty for gay people that was an extension of the history of homosexual discrimination and marginalisation. It was this history and this fear that shaped gay community responses to AIDS. A social group that did not have a history of discrimination similar to that of gay men, would have been unlikely to responded in the same way.

36 Levinia Crooks interviewed by the author on 28 January 2005.
Identity, Collective Memory and Political Opportunity

Knowledge of the shared history of a group of people tends to be carried through generations. Memories don’t exist only in individual minds, but are cultural artifacts reproduced through stories and written texts. The knowledge held by individuals within any one group produces a collective memory of past events, and the history of that group of people shapes how they live in the present – their cultural practices and social position. Describing this, Melissa Williams writes: “Members of marginalised groups carry the burden of their history with them in their day-today lives. The history of discrimination is a residue deposited within and among the structures of social life...” (Williams, 1998:182). Collective memory contributes to the formation of identity and an individual’s sense of where he or she, and the groups to which they belong, are positioned in the social world (Harris, 2006:20-24).

Similarly, Fredrick Harris describes this as the “hidden transcript” of marginalised groups. The shared past is articulated within that group through informal ties, producing a collective interpretation and understanding of past and current events. Gay men and women, for instance, through personal observation and absorbed collective memory tend to be acutely aware their social position. This sense of history and knowledge of social position is experienced both through intellectual comprehension of the social world and through emotional sensation (such as feelings of not belonging or a fear of rejection). According to Harris, it is collective memory that often informs the cultural ‘frame’ of a social movement, or the articulation of social reality produced by social movements. In other words, a movement’s frame is in part derived through the history, and felt experiences, of a group of people – a
product of knowledge that has been circulating “beneath the radar” for many years (Harris, 2006:20). Harris suggests that, “When structural opportunities expand for collective action and the hidden transcript of marginal groups publicly resurfaces, past events may contribute to the articulation of grievances and inform strategies for collective action” (Harris, 2006:20).

The fear of AIDS was as much a product of the social history and social position of gay men and lesbians as it was about the terror of this unknown, fatal disease. People reacted to the felt-experience of injustice that had long been part of life for gay men and lesbians. But also, within the gay community, there was a collective sense that people needed to protect themselves from the social/political ramifications of AIDS. In the beginning this was not necessarily a clearly articulated political position so much as an undercurrent of knowledge about gay history that circulated within the community compelling people to take action. As activist Ken Davis put it, “So my generation ... I don't know what we thought we were going to achieve. But we didn't have a choice because we thought we were going to be locked up or dead” (Davis, 200437). That is, the gay community mobilised around the AIDS issue in a manner that could be described as fearful and defensive, not necessarily in pursuit of a clear political agenda or expressed set of goals.

Before the [HIV] treatment issue was addressed, people were turning over at an incredible rate. So a lot of the debates and discussion were being made fresh by people at the end of their lives, frantically trying to get things fixed.

37 Ken Davis interviewed by the author on 5 November 2004.
This didn’t necessarily build into a coherent set of objectives because in the face of death what objective can you have. So a lot of it was about being very angry and frustrated and not liking the hand the world had dealt. And not liking the way the government was responding, or community organisations were responding (Rankin, 2004)\textsuperscript{38}.

Yet the history of homosexual discrimination also provided an important ‘political opportunity’ for the AIDS movement in that previous activism around issues such as law reform and police treatment had established both political awareness among the gay community, together with tangible experience in collective mobilisation.

\textit{The immediate response from the gay community and the fact that there was a gut response, but it was a united one, was critical. The fact that we had enough of an organised gay community to have a gay press, a gay bookshop, gay venues – we even had the argument about gay community versus gay movement. That was all going on. There was enough of that stuff and enough political self-awareness so that when this was on top of us we actually had a framework to respond with. It wasn’t like we were just some little atoms of people, there actually was a centre – geographical and political – a heart where we knew the gay community was. And we knew each other very well. I don’t know if we trusted each other very well, but I think we knew each other}

\textsuperscript{38} Ian Rankin interviewed by the author on 26 July 2004. This quotation was in the context of a general discussion about the AIDS response in Australia.
well enough to have a good working relationship. And that was enough to get started (Carswell, 2005b)\textsuperscript{39}.

Additionally, the leaders of the AIDS movement were on the whole well-educated men, skilled in political negotiation, many of whom lived in a relatively privileged position financially and were operating from a position of political confidence. So despite the marginalised status of homosexuality, activists had a sense of entitlement that informed their activism (Cohen, 1988:12).

\textit{I think had we not come to it with activism and some confidence or confrontation and sense of our rights ..., and I think as young gay men we often didn't understand ... I think we came to it with an arrogance, that we couldn't believe we didn't have rights for a whole lot of stuff – other disease or disability groups were putting up with a whole lot of stuff that young gay men didn't think they had to put up with – particularly young rich gay men, suddenly impoverished. But we demanded ... often we demanded ... stuff with no conscience that other people didn't have those things. And a lot of the education around pension and housing and stuff worked because gay men didn't realise that that was the deal – this is what another impoverished or ill person is putting up with. We demanded all this special treatment. The end result was that it improved services for a lot of people. And it allowed other people to follow a bit of a path of taking on the medical providers or the social providers and saying the nature of the relationship with the customer is

\textsuperscript{39} Phil Carswell interviewed by the author on 23 July 2005.
different. And that's a good product of the activism. But we didn't strategise that, we just did that because we didn't know any better (Davis, 2004).\textsuperscript{40}

Conclusion

When AIDS first appeared in Australia, the history of discrimination and the tenuous legal status of homosexuality created a collective sense of fear. People were motivated to take action around AIDS because they understood the fragility of social rights for gay men and lesbians and had a personal and emotional stake in the issues. This was the beginning of mobilisation around HIV/AIDS in Australia.

This chapter has shown that throughout Australia’s history, homosexuality has been a regular topic of interest within the media and public discussion. But, prior to HIV/AIDS, this discussion usually occurred only in medical and legal terms, and there were very limited opportunities for gay men and lesbians to articulate publicly their own identities and opinions. Gay men and lesbians tended to be spoken about rather than spoken to in mainstream public discussion. In later chapters I argue that the AIDS movement was significant to the history of homosexuality in Australia because it created opportunities for gay people to develop a public presence on their own terms. While gay and lesbian activism had certainly been present in Australia prior to the 1980s, HIV/AIDS created an urgent and very apparent reason to push for social change. Many more people became involved in gay activism than ever had before.

\textsuperscript{40} Ken Davis interviewed by the author on 4 November 2004.
This chapter has also shown that the emergence of the AIDS movement occurred in an historical context. While AIDS activists were motivated by the immediate threat of AIDS, there was a long history to homosexual discrimination that informed the lives of gay men and lesbians. The AIDS movement should be seen as part of this history. In other words, the AIDS movement — and the movement 'frame that emerged — was a product of the intersection between gay and lesbian history and the social insecurities generated by AIDS. In the following chapter I argue that this 'intersection' created an opportunity for reshaping public perceptions of gay men and lesbians. The AIDS movement became a new social force that influenced the construction of knowledge and homosexuality.
Chapter Four: Politics, Fear and Innocence – the Movement Responds

Of course a lot of the epidemic is lived out in what I’d called the public imagination (or imagination of various publics) and a lot of that is mediated through the press – the TV, the Alan Jones’s (Rankin, 2004).41

The notion that there was an inherent link between homosexuality and HIV/AIDS, although erroneous, inevitably meant that social and political responses to the virus were influenced by attitudes toward gay men. Assumptions about ‘what gay men are like’ became part of debates concerning the type of actions Australian society should adopt in order to contain the spread of HIV. Not surprisingly, the AIDS movement found many of its ‘battles’ were waged against the way in which gay men were portrayed, both in the media and in debates about HIV/AIDS. However, while negative and discriminatory attitudes toward homosexuality certainly represented a threat to the civil rights of gay men and lesbians, there was a positive dimension for the AIDS movement in the increased public attention on homosexuality. It was perhaps the first occasion in Australia’s history where gay people had an organised, consistent and high-profile presence in debates about homosexuality. Discussions that would once have been held between medical professionals, legal experts and police, now involved gay people on a regular and consistent basis.

The previous chapter discussed the emergence of AIDS activism, making the point that it was a product of homosexual history in Australia, and that the AIDS movement ‘frame’ which developed cannot be fully appreciated outside this

41 Ian Rankin interviewed by the author 26 July 2004.
historical context. That is, the AIDS movement mobilised with reference to a long history of homosexual discrimination and marginalisation in Australia. This history led AIDS activists to view HIV/AIDS as a virus intimately connected with issues of social justice and human rights. This chapter looks at how gay and lesbian rights, and the recasting of stigmatised gay and lesbian identities, became defining features of the AIDS response.

Blood Politics: Beginnings of the AIDS Movement

AIDS screamed into mainstream public consciousness in the early 1980s when it became known that people could acquire the virus through blood transfusions or donated blood products\(^\text{42}\) and fears were aired that the blood supply in Australia could already be infected. When this news hit the media, the public began to realise for the first time that AIDS could spread beyond populations of gay men and ‘junkies’. Heterosexual adults and children were also vulnerable.

The first newspaper report on the possibility that the Australian blood supply could be infected appeared in *The Australian* on 2 May 1983, with an article discussing concerns of the British Health Authority that blood being imported from the United States may contain AIDS. As Australia did not rely on imported blood products, this article did not receive much reaction. A short while later, however, Dr Gordon Archer, Director of the Sydney Blood Transfusion Service (BTS) put out a public call for ‘promiscuous’ homosexual men to voluntarily stop donating blood, declaring

\(^{42}\) This occurred before the antigen for HIV was identified, although at the time there was a general medical consensus that AIDS must be a blood borne virus due to the number of people who appeared to have acquired AIDS through intravenous drug use.
in a television interview that it was a “virtual certainty” that the blood supply in Australia was already infected with AIDS\textsuperscript{43}. Archer’s call made front-page news across the country \textsuperscript{44} (Cook, 1983:1; Ballard, 1999:249; Sendziuk, 2001:78).

Archer made his call at a time when there was no test available to screen blood for HIV – indeed HIV had not yet been identified as a virus. The only step authorities could take to prevent infection was to stop people who may be at higher risk of having AIDS from donating. Despite this, many members of the Sydney gay community were angered by Archer’s announcement – not because they opposed having a policy on restricting blood donation, but because they felt those most affected by such a policy should be consulted about its terms and potential impact (Baxter, 1993)\textsuperscript{45}. In 1983 homosexuality was still on the criminal code in NSW and there was no legal protection from discrimination. The actions of the BTS seemed to offer further political fuel to those who opposed civil rights for gay men and lesbians. A member of a community organisation called the Gay Solidarity Group contacted Archer to request a meeting to discuss BTS policies. One option they

\textsuperscript{43} Archer’s call came before there were any identified cases of blood product transmission in Australia although such transmission was known to have occurred in the United States and there was a realistic probability that Australia would face a similar problem (Sendziuk 2001:78).

\textsuperscript{44} Some within the BTS did not support Archer in his assertions. For example, the chair of the National Blood Transfusion Service (NBTS), David Penington, publicly responded that there was no risk of Australia’s blood supply being infected with HIV because blood donation in Australia has always been entirely voluntary (apart from a short lived experiment with a professional donor panel in 1938) (Ballard 1999: 245). Penington was obviously making the assumption that the type of people who would be inclined to sell their blood for cash would be drug users or other people at greater risk of HIV.

\textsuperscript{45} Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.
wanted to investigate was whether Archer would be amendable to investigating the feasibility of introducing ‘surrogate screening’ for hepatitis B, rather than maintaining a policy that singled out particular groups. The Blood Bank had, for some time, been testing all blood donations for the hepatitis B virus – the antigen for which had been identified in the late 1960s. Ironically, this meant that in the 1980s there were large numbers of gay men who regularly donated blood, as they had been encouraged to do so as a means of being tested, anonymously and without cost, for hepatitis B and syphilis. The logic of surrogate testing was that if a person had been exposed to hepatitis B, there was a reasonable chance they had also been exposed to AIDS (Ballard, 1999:247).

[The] trouble with the blood stuff was that we said as soon as you say that you can’t donate if you are promiscuous homosexual, you’re really missing the point of how to screen blood and that no one thinks of themselves as a promiscuous homosexual ... If you want to formulate something that will exclude, let’s talk about it. And the truth is that after that exclusion of promiscuous homosexuals infection rates went up. And I don’t think that was deliberate at all. I think people genuinely didn't understand and wanted to make a contribution and that gay men had been specifically targeted for blood donation for a decade before. So it was a real mess all of that (Davis, 2004).46

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46 Ken Davis interviewed by the author on 5 November 2004.
Archer refused to meet with the Gay Solidarity Group. In response to this, participants at a Gay Rights Lobby (GRL) meeting organised a picket of the offices of the Sydney Blood Bank\(^{47}\). The picket was held on 13 May 1983. Placards and leaflets demanding “Ban the Bigots, Not the Blood” were handed out stating that the ban on gay donors could be counter productive as ‘closeted’ gay men may feel the need to donate blood to prove their heterosexuality, particularly in a situation where they were donating with work colleagues as was a common practice (Sendziuk, 2001:79). Unfortunately for activists, the picket turned out to be largely counter-productive as gay men were portrayed as putting their own interests above public health.

From a public relations point of view for the gay community [the picket] didn’t seem to me to be a sensible course of action. I suspect quite a lot of people must have shared those views and the picket didn’t attract that many people really. There were some people who had been politically active. But it certainly didn’t seem to attract a broad consensus ... I think it was a little bit unfortunate in a sense also because then it gave the people who wanted to call themselves ‘innocent victims’ the opportunity to blame the community: “They have these pickets and want to donate blood”... It probably fueled fears that some people were deliberately donating blood, which I don’t think was the case (Lowe, 2005)\(^{48}\).

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\(^{47}\) The Melbourne Blood bank did agree to a meeting with gay community activists. There were no similar protests to those that took place in Sydney (Carswell 2006).

\(^{48}\) David Lowe interviewed by the author on 12 July 2005.
Following the unsuccessful picket, a number of people and groups got together on 15 May 1983 to discuss how to proceed. These groups included the Gay Rights Lobby, the Gay Counselling Service, the Gay Solidarity Group, the Metropolitan Community Church\textsuperscript{49} and the Gay Business Association. From this meeting the NSW AIDS Action Committee (AAC) was established (Sendziuk, 2003:34 and 74; Baxter, 1993)\textsuperscript{50}. The first success of the Sydney AAC was convincing the NSW Minister for Health to establish a ministerial advisory committee – the AIDS Consultative Committee. Membership of this committee included NSW Department of Health staff, medical specialists and representatives from the Sydney AAC (Sendziuk, 2003:35).

\textit{And that was the genesis of AIDS activism, that small (inappropriate) picket of the blood bank that I wasn't at ... that precipitated the state government having to have a meeting between government, medical people and gay men} (Davis, 2004)\textsuperscript{51}.

A few weeks after the Sydney Blood Bank picket, the National Blood Transfusion Service (NBTS) released a statement urging sexually active homosexual men, intravenous drug users and sexual partners of these people to abstain from donating. The NBTS had been careful to avoid a community reaction similar to that in Sydney.

\textsuperscript{49} Metropolitan Community Church Sydney is a Christian church that operates specifically to reach people excluded by established religious groups on the basis of sexuality. The MCC was an active part of the gay and lesbian community in the 1980s (and still today) and participated in AIDS movement initiatives.

\textsuperscript{50} Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.

\textsuperscript{51} Ken Davis interviewed by the author on 4 November 2004.
by expanding the groups being asked not to donate beyond homosexual men and using the term ‘sexually active’ rather than ‘promiscuous’. The Blood Transfusion Services in other states also began to ask donors to sign declarations stating that they did not belong to the risk groups identified by the NBTS (Ballard, 1999:249).

The actions of the NBTS did little, however, to resolve the tension around HIV and blood donation, and the issue dominated headlines again in July 1984 when the first Australian case of AIDS known to have been acquired through a blood transfusion was diagnosed. In this case, the blood donor, who was tracked by the Blood Transfusion Service, was a gay man who acknowledged that he was aware of the call for ‘promiscuous’ gay men not to donate, but had not considered himself to be promiscuous. A short while later the media reported that the same donor’s blood had also been used in the preparation of Factor 8 and a number of people with Haemophilia were being tested for AIDS (Sendziuk, 2001:82).

**Prejudice and Queensland Babies**

AIDS began to receive more consistent public attention in November 1984 when the Queensland Government announced that three babies had died after receiving AIDS infected blood, and that a donor known to be homosexual was to blame (Langley and

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52 In Australia, a total of 172 cases of HIV acquired through blood transfusions had been identified by the end of 1995 and some 264 people had been infected through blood products used to treat haemophilia (Ballard 1999: 256). This represents approximately 30 per cent of Australians with haemophilia who treated their condition with blood products between 1980 and 1984. People with haemophilia were, in the 1980s, at particularly high risk of HIV infection as Factor 8, the product used to treat haemophilia, was made using the blood of a large number of donors. Hence people using Factor 8 came into contact with the blood of many more donors than those who had a blood transfusion or received organ donations (Sendziuk 2001: 82).
Rice, 1984:1). Probably not coincidentally, the announcement came in the middle of a federal election campaign and it quickly became a highly politicised issue. Public figures and political leaders started weighing in on the debate about how to deal with AIDS, much of which focused on determining appropriate means by which to control or punish the actions of homosexual men who donated blood. For instance, in his speech, opening the National Party’s federal election campaign in Victoria, the leader of the party, Ian Sinclair, publicly declared that: “If it wasn’t for the promotion of homosexuality as a norm by Labor, I am quite confident that the deaths of these three poor babies would not have occurred” (Davis and Birnbauer, 1984:1; Ballard, 1999:252). The ultra-conservative Queensland Premier at the time, Sir Joh Bjelke-Petersen, also blamed the Federal Labor Government’s stance on homosexuality, commenting that: “The Labor party is as much to blame with their acceptance of that type of low and disgusting lifestyle. And Mr Hawke is to blame by promising equal government support for homosexual marriages” (Canberra Times, 1984a: 1). ‘Sir Joh’ was backed by his Health Minister Brian Austin who, in discussing what punishment should be delivered to members of known ‘AIDS risk groups’ who donated blood, stated: “You can’t legislate to stop murder. You can put up signs telling people it’s illegal to murder someone but that won’t stop it” (Canberra Times 1984:1; Northern Territory Times 1984:1).

The Blood Transfusion Service attempted to allay the blame being placed on the individual whose blood donation had infected the ‘Queensland babies’ by describing the donor as “a person with a civic conscience” who had not realised they were an ‘AIDS carrier’. A BTS official was reported as saying: “He [the donor] had been very upset by the revelation and was now suffering extreme regret” (Langley and
Rice, 1984:1). Nevertheless, the Queensland government, fuelled by the media, vitriolically continued to pursue punishment for the donor and a punitive approach to protecting the blood supply.

Twenty-four hours after the babies’ deaths had been reported the Queensland government passed legislation imposing criminal sanctions for false declarations by blood donors. If someone were to lie about their history of homosexuality or drug use when donating blood, they could now be held criminally liable (Langley and Rice, 1984:1). Despite the reluctance of other state health minister’s to impose legal regulations on blood donation, they agreed that all states needed to offer the same blood protection as Queensland. The legislation was adopted by other states a month later at the State Health Minister’s Conference. Australia was the only country in the world to have introduced such laws (Ballard, 1999:252-253).

There are two ways to look at this legislation. The first is that it was a pragmatic response to the need to protect the blood supply in the absence of any other means to screen for AIDS. While this was certainly the case, the legislation also suggests that authorities felt that the identified risk groups (gay men and intravenous drug users) needed to be controlled. The legislation was introduced amid a politically charged public debate within which prejudice toward gay men was overt. As Ananda Hall comments: “A translation from moral narrative to legal discourse has taken place in response to the HIV pandemic” (Hall, 1998). Furthermore, homosexual discrimination no doubt made it more politically risky for the state ministers not to introduce punitive action, than it was to introduce it and certainly state governments,
particularly in Queensland, wanted to be seen to be taking decisive action around AIDS.

Media dialogue supported the legislation, revealing a mistrust of gay men and their capacity to act responsibly. Headlines also suggested that gay people were deliberately and maliciously infecting the blood supply: “Gays Accused of Giving Blood out of Spite” (Daily Telegraph 17 November 1984, quoted in Ballard, 1999:253). This line wasn’t isolated to the tabloid press. The Australian broadsheet, for instance, ran an editorial on 17 November 1984, that stated:

The chief medical officer of the NSW Health Department, Dr Tony Adams, believes that there may be a minority of homosexuals who are donating blood to rebel against society. It is hard to accept that anyone could be so vindictive as to take such action but when added to the revelation by a Sydney gay activist that some homosexuals who have recently given blood are now refusing to identify it for fear of persecution, it can only add fuel to the fire (Editorial, 1984b:24).

An editorial in the Brisbane Courier Mail on the same date suggested that gay men were being irresponsible or selfish in their appeal for civil rights in the face of what could amount to a life or death situation for many people. This was a common theme – that calls to punish gay men weren’t based on homophobia, but the sensible actions of public health authorities. AIDS, in this sense, came to obscure a moral agenda. The Courier Mail editorial stated:
Clearly the medical authorities, both here and in other states, are doing everything possible to limit the spread of AIDS ... Sadly, however, the actions of some members of the homosexual community have lacked responsibility and concern ... Blood banks have appealed to male homosexuals not to give blood. Yet it seems for a number of reasons, these appeals have been ignored ... It was not so long ago in our history that patients suffering other socially-unacceptable, contagious diseases, such as tuberculosis and leprosy, were locked away for what was considered the community good. No one is suggesting that this should happen to homosexuals, but the aggressive activists in the movement should not be surprised if there is a violent community reaction to their cause as a result of this serious public health problem (Editorial, 1984a:4).

Reflecting similar ideas, The Australian ran an opinion piece in November 1984, written by high profile conservative commentator B.A Santamaria, in which he claims that the intention of his column was “not to pass moral judgment on homosexual acts”. Rather, he writes: “The sole question with which this column is concerned ... is that of public health”. The piece goes on to argue that by claiming the right to privacy and confidentiality in order to ensure protection from discrimination, gay men were asking for extraordinary privileges. He writes that: “Where public health is concerned, the infringement of the privacy of individuals is rightly held to be secondary to the threatened ravages of epidemic disease.” Gay men, he argues, should not have the right to demand civil freedoms if this contravenes public health priorities (Santamaria, 1984:11).
practice was to present gay men as inflicting the illness on others, through intention or carelessness. In this way, beliefs about homosexual immorality and deviance played into the construction of AIDS in the public’s imagination. HIV prevention was used to justify the curtailment of rights for gay men and lesbians, obscuring the moral opinion embedded in these calls. Activists who demanded a right to privacy and protection from discrimination were portrayed as acting against public health interests.

Community and Organisation: The Movement Develops

By the time the ‘Queensland babies’ crisis erupted the AIDS movement was well organised, operating through several state-based organisations – the Victorian AIDS Action Committee (VAAC), the NSW AIDS Action Committee (NSW AAC) and similar activists groups in other states 53.

As noted previously, the first meeting of the Victorian AIDS Action Committee (VAAC) had taken place at the Laird hotel in Collingwood in July 1983 (Carswell, 2005b)54 55. On 4 December 1984, the VAAC held its first major public forum since

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53 This analysis focuses predominantly on Sydney and Melbourne as ACON and the VAC were the largest AIDS organisations and both provide a clear example of the strategies undertaken by the AIDS movement. There were, however, organisations similar to VAC and ACON that received government funding in Perth, Adelaide and Canberra. The Queensland story is a little different as this state was subject to the reign of ultra-conservative Premier Joh Bjelke Petersen throughout much of the 1980s. The Queensland Government for many years actively campaigned against the involvement of the gay community in the AIDS response. Homosexuality remained on the criminal code in that state until 1990. Nonetheless, there was a community response to AIDS in Queensland. The Federal Government was able to override Bjelke Petersen to some extent by funneling money to the Queensland AIDS council through a religious charity (Carswell 2005b).

54 Phil Carswell interviewed by the author on 23 July 2005.
this inaugural meeting and around 600 people attended. At this meeting a decision was made to transform VAAC into what is now known as the Victorian AIDS Council (VAC). The VAC operated under a more formalised, incorporated structure, and the change enabled the organisation to receive government grants (the Victorian State Government was unwilling and unable to fund an informal volunteer organisation) (Carswell, 2005b; Carswell, 2005c; Altman 1990:4). Funding from the Victorian State Government was made available to VAC from 1985 through a grant from the State and Federal Government joint funding initiative.

A telegram arrives for me as VAC President announcing a $50,000 Commonwealth grant. We all cheer and wet our pants at the same time. This is the largest amount of money anyone of us had thought possible ... This also saw the formation of the Gay Men’s Health Resources Project, which later became the Gay Men’s Health Centre (GMHC) and the recipient of most of

55 From this date, the VAAC began organising educational initiatives, producing ‘safe sex’ information and campaign materials. Volunteers were recruited for care, support and general assistance even before VAAC had any clients (the official AIDS case load in Australia at the end of 1983 was only seven though this number increased significantly throughout the following year). The first fundraising efforts focused on improving patient facilities at Melbourne’s Fairfield hospital, which was the main hospital for people with AIDS, starting with the run-down patient lounge at the end of the Ward Four corridor (Carswell, 2005b; Tobias, 1988:2:Altman, 1990:4).

56 Phil Carswell interviewed by the author on 23 July 2005.

57 Excerpt from personal notes made by Phil Carswell for a presentation on the history of the AIDS epidemic at Sydney University in 2002.

58 Funding was tied to specific projects – with stated expected outcomes and a limited timeframe. VAC was able to secure funds for administration of the organisation in 1986 (Morcos, 1986: 13). The same year, VAC negotiated with the State and Federal Ministries of Housing to secure a property in which to accommodate people living with AIDS. VAC would provide nursing, 24 hour care and support for residents (Carr, 1987:6).
A similar process occurred in Sydney with the NSW AAC being reformed into the AIDS Council of NSW (ACON) in February 1985 (Sendziuk, 2003:74). ACON’s foundation meeting was held at the Teachers Federation Hall in Sussex street in the city and was attended by over 500 people (Baxter, 1993). ACON was an amalgamation of several organisations that had been set up in response to HIV/AIDS including the AAC, the Bobby Goldsmith Foundation, the Community Support Network (CSN) and Ankali support service (Baxter, 1993; Ariss, 1997:30). By

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59 Excerpt from personal notes made by Phil Carswell for a presentation on the history of the AIDS epidemic at Sydney University in 2002.

60 Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.

61 Bobby Goldsmith was a gay man who died in June 1984 of medical complications caused by AIDS. Bobby was active in Sydney’s gay scene and community activities (particularly sporting activities) and had a wide range of friends. When Bobby became ill, a group of his friends arranged care and support for him at his home so he was able to avoid hospital. When medical equipment was needed to assist his care, Bobby’s friends raised funds for things such as a wheelchair, commode and special support mattress. When Bobby died the Bobby Goldsmith Foundation Inc. (BGF) was established in his name. BGF is a fund which supports people with AIDS-related illnesses to be cared for in their homes (BGF, 1999).

62 Community Services Network Inc (CSN) is a volunteer-based, community group that provides in home-care for people with AIDS-related illness (ACON, 2006). CSN developed from the AIDS Support Group and AIDS Home Support that were established by Terry Goulden, a founding member of the Gay Counselling Service. These support services ran alongside the AAC, but were kept separate from political activities as Goulden was concerned that the politics might alienate potential allies. However, when the AAC was reformed into ACON in February 1985, these care and support services were integrated with the other functions of ACON. As an example of the extent of volunteer-

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1989, ACON and the CSN had around 700 members in NSW. This included branches in Sydney, Newcastle and the North coast. ACON’s governing council included 12 elected committee members (unpaid) and the organisation had 25 full-time staff (ACON, 1989; Baxter, 1993).65

In 1985, representatives from AIDS Committees and councils from across the country, who had been attending the First National AIDS Conference, passed a vote to establish a national federation of AIDS organisations, to be named the Australian Federation of AIDS Organisations (AFAO) (Carswell, 2005b).66

AFAO, VAC, ACON and other community-run HIV/AIDS organisations across the country, such as the AIDS Action Council of the ACT and the Western Australian AIDS Council, formalised and centralised the base from which activists worked. As Graham Willett writes:

labour coordinated by CSN, throughout the 1990-1991 financial year CSN staff and volunteers did 11,874 shifts for their 173 clients. This amounted to over 72,000 hours. The vast majority of these hours were dedicated to direct care of clients in their homes (Malcom, 1991).

63 ‘Ankali’ is an Aboriginal word meaning ‘friend’. The Ankali project was established in 1985 in Sydney. The project trains volunteers to provide one-on-one support to people with AIDS as well as their partners, families and friends. Ankali is now linked to the Albion Street Centre, an HIV/AIDS service and medical clinic funded by the NSW Government (SESAHS, 2006).

64 Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.

65 Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.

66 Carswell notes that the Queensland AIDS Committee (QuAC) had some initial reservations as their membership was broader than the gay community and were concerned that AFAO was primarily gay oriented (Carswell 2005b).
The work was transforming the activists as much as they were transforming the world. It is not an accident that a shift from ‘action committee’ to ‘AIDS Council’ took place in late 1984 and early 1985 as the government and gay activists started to work more closely together. The shift in nomenclature marked a shift in outlook by the organisations and those running them. Adam Carr, who first proposed the change, saw ‘council’ as evoking respectability and authority, a gathering of experts and their expertise, appealing more to governments, bureaucracies and medical professionals than action committees (Willett 2000: 175).

In the early 1980s, the AIDS movement quickly and strategically established a dialogue with the Federal Government. For example, in September 1983 a meeting was organised between the Federal Health Minister, medical researchers and members of the NSW and Victorian AACs. At this meeting Health Minister Blewett made it clear that the Federal Government was prepared to denote a formal role for the community sector in the AIDS response if they were willing and capable to undertake this. With the relationship already established, activists were later given an opportunity to meet with Blewett and his advisor Bill Bowtell to advocate their position on the ‘Queensland Babies’ scandal in 1984 (Carswell, 2005a; Carswell, 2005b).

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67 Although Carswell notes that because the AACs were still in their infancy at the time and not highly organised so the community did not follow up on this meeting as effectively as they could have (Carswell 2005b).

68 Phil Carswell interviewed by the author on 23 July and 17 December 2005.
Then in late 1984, representatives from the Victorian and NSW AIDS Action Committees, Phil Carswell and Lex Watson, were invited to join the new National Advisory Committee on AIDS (NACAIDS). The committee was set up to advise the government on human and social aspects of AIDS. It was chaired by prominent Australian media personality Ita Buttrose. Other appointees to NACAIDS included Jennifer Ross from the Haemophilia Foundation, Anne Kern from the Commonwealth Health Department, representatives from the NSW and Victorian Health Departments, the Australian Medical Association and the Royal Australian Nursing Federation69 (Altman, 1992:57; Carswell 2005b).

Their role on NACAIDS gave the AIDS movement a legitimate place in AIDS policy-making. As Carswell points out, the fact that the AIDS movement had two people on NACAIDS meant they were able to both move and second motions, giving them a reasonable amount of power around the committee table (Carswell, 2005b)70. Although they certainly adapted to their new situation, the level of authority afforded to the AIDS movement through their role on NACAIDS was unanticipated by many activists. A number of people had previous experience in political lobbying, but to actually sit on a government advisory body and develop personal relationships with high-level decision makers, including a Federal Government minister, was a new experience.

69 Now the Australian Nursing Federation.
70 Phil Carswell interviewed by the author on 23 July 2005.
I think, over time, the community sector has become more confident that it is entitled to be funded. Certainly in the early-to-mid 1990s I still had a sense that people were surprised that we were allowed to sit around ministerial advisory tables or comment on research programs etc. We’d come out and boldly claim it. But everyone would still be a bit surprised when it actually happened. I think during the course of the ’90s people became more comfortable with the idea that the community sector was valid, should be represented, did have something to say and something to contribute (Rankin, 2004).  

Building a working relationship with the Federal Government proved to be an extremely important tactic of the AIDS movement in terms of gaining access to funding and political power, and establishing the public profile of activists.

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71 Ian Rankin interviewed by the author on 26 July 2004.

72 Despite the political authority afforded by the AIDS movement’s relationship with the Federal Government, questions began to be raised about the limitations imposed on the movement once they were operating with government funds and had activists sitting on official advisory boards. There were fears that the movement had become ‘co-opted’ by government and therefore less able to advocate independently the interests of the gay community. Although I do not discuss these issues further in this thesis, they are important considerations in terms of studying movement building in the longer term. In Australia, concerns that government funding had the potential to demobilise collective action were, to some degree, justified when the Liberal Party won the federal election in 1996, under the leadership of John Howard. The Howard regime began a program of cutting funds to non-government organisations. Organisations that publicly criticised the government, or were actively campaigning against government initiatives, began to feel that their funding was under threat. Many argue that the political efficacy of non-government agencies is significantly hampered in the current political climate in a way that it wasn’t under the ALP government of the 1980s and early 1990s. As AIDS organisations are still partially funded by the Federal Government, it is argued that the capacity of the AIDS movement has been undermined by the reliance of AIDS organisations on government funds. Even if activists not affiliated with a formal AIDS organisation were to take action against the

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However, despite their formalised status there was no doubt that it was the strong base of community support that gave the AIDS Councils their political strength in the 1980s and early 1990s. The AIDS movement continued to attract a much broader constituency than those involved directly with the formal organisations. Large numbers of non-aligned activists took part in volunteer community work and traditional protest strategies such as street-demonstrations and lobbying continued to be a feature of AIDS movement activity.

Yes I mean I think what happened is in Australia a number of people came forward, mainly gay men but a couple of exceptions, Margaret Duckett for example who just emerged and had skills in lobbying. But a number of gay men who had the skills cause of what they had done in the past – lobbying, policy, people who knew how government worked came forward and had skills and were effective. But also there were groups of gay men who ... didn't have any of those skills. They were not particularly sophisticated but were brave enough to speak out, turn up and that was very important (Whittaker, 2004)\textsuperscript{73}.

government around AIDS, it arguably could threaten the funds of organisations such as ACON and VAC (Staples 2006:2, Tabone 2004). That being said, most people interviewed for this thesis who were involved with ACON and VAC in the early 1980s acknowledged that the partnership with the Labor Federal Government in the 1980s was politically advantageous and progressive – even radical – for its time (Davis 2004).

\textsuperscript{73} Bill Whittaker interviewed by the author on 6 November 2004.
AIDS and Gay Politics

The AIDS Councils were very much integrated with the gay community. They had a broad support base and many community members were involved. The gay press also ensured that the community was consistently made aware of what the AIDS councils were doing. Moreover, HIV/AIDS was an issue that drew the gay community into political action in a way that other issues never had. Literally hundreds more people were politically active around HIV/AIDS than had ever been around issues such as law reform, and there was a high level of awareness among gay men about the politics of HIV/AIDS, even those with no direct connection to AIDS activism. Indeed, throughout the 1980s gay politics became enmeshed with the politics of AIDS. As one of the founding members of ACON, Lex Watson, once wrote: “AIDS has fundamentally changed the style, the content and, indeed, the whole notion of gay male politics” (Watson, 1988:13). Watson remarked that while issues such as gay law reform and anti-discrimination had always been considered politically important, there were many gay men who never felt compelled to take an active interest in them.

[AIDS] has affected all gay men in a way in which law reform, nice idea though it was (and much though I spent years doing it), did not really do. Many gay people thought anti-discrimination was wonderful, many people felt more confident because of it, many people were very glad they had it. But it didn’t, very often, directly and immediately, change their lives. AIDS has. And AIDS has consequently rewritten the gay male script in a way that nothing else has. Perhaps one could argue that the Mardi Gras in Sydney, as a
gay community event, has come the closest to this far-reaching impact, but AIDS has a very particular resonance (Watson, 1988:13).

The AIDS councils became a major organising body for the gay community. Although the government funding they received was primarily directed towards HIV prevention initiatives, the AACs and the AIDS Councils did not lose focus on their objective of protecting the rights and freedoms of gay men and lesbians. Their political intent in this respect was clear from the beginning (Michael, 1987:9). For example, when the Sydney AAC was established, they announced their formation in a letter to Neal Blewett stating that the AAC aimed to, among other things, “monitor available information on AIDS and provide non-alarmist information to both the gay community and the wider media in order to counter the political attacks on homosexuals that had become adjunct to the AIDS debate” (cited in Sendziuk, 2003:74). In Melbourne, a media report in The Age, titled “Gays Form AIDS Group”, stated:

74 This is not to say that the AACs, VAC or ACON were against working with other groups or didn’t see the importance of approaching HIV/AIDS more broadly than the gay community. Over time, the VAC and ACON began to work with other groups affected by HIV including women, heterosexual men and Indigenous people. However, historically it was the gay community that developed these organisations and a large part of their raison d’être was the protection of gay rights.

75 The AACs were also given a mandate from the gay community to speak on their behalf. Public meetings took votes allowing the AACs to formally represent the gay community, which helped to sideline those who professed to be spokespeople without any community backing (such as Paul Dexter, who claimed to be head of an organisation called the ‘Gay Army’ although he was the only recruit) (Carswell 2006c).
Melbourne’s homosexuals yesterday announced the formation of a special group to combat what it regards as ignorance and hysteria about acquired immune deficiency syndrome, AIDS. A spokesperson for the Victorian AIDS Action Committee, Mr Adam Carr, said that the group has been set up to speak for the homosexuals in any working groups studying AIDS, to counter incorrect information being spread about the disease and to resist any attacks on homosexual people prompted by the disease. “We reject any suggestions that AIDS is in any way a gay plague or other similar phrases used out of ignorance or malice,” Mr Carr said. “We reject any suggestions that homosexuals or any other minority group are responsible for the outbreak of this disease. We will defend the gay community from these attacks” (Age, 1983:5).

The formation of AIDS Councils, and the subsequent funding of these councils by the Federal and state governments meant two things for gay and lesbian rights. Firstly, for the first time in Australia’s history, groups advocating gay and lesbian rights received significant levels of government funding. Secondly, the political influence of these groups gave them the capacity to establish a strong media profile. Through this, they challenged some of the negative discourse that had been emerging about gay men in relation to HIV/AIDS. The Councils demonstrated to the public that, far from adopting the irresponsible or malicious response to AIDS that had been depicted in the media through the ‘Queensland Babies’ scandal, gay men were actually taking responsible and informed action to combat HIV/AIDS.
The AIDS councils ensured that the media published information about their initiatives and amidst the articles that expressed concerns that gay men were spreading AIDS, more positive stories began to appear. For example, on 31 May 1983, the *Launceston Examiner* ran the headline, “Homosexuals to Fight Lethal AIDS”. The article stated that: “Sydney’s homosexual community has called for a national seminar to find how best to combat the mysterious AIDS disease that has killed at least 600 people in the US” (Needham, 1983:6). The *West Australian* newspaper in the same year reported on actions being taken by the Campaign Against Moral Persecution (CAMP) to inform gay men about AIDS. The article noted that medical specialists had commended a bulletin prepared for gay men by CAMP (*West Australian*, 1983:23). In 1985, the *Sydney Morning Herald* ran a headline that read, “Gays want Govt (sic) Help to Prevent AIDS”. The story went on to explain why the AIDS movement was calling for government funding for community AIDS initiatives. It also mentioned that 60,000 brochures about AIDS were already being distributed by the AIDS Councils.

**Innocence and the Framing of AIDS**

Despite affirming publicity such as this, the capacity of the AIDS movement to challenge the anti-gay sentiment that surfaced in response to AIDS was continually tested throughout the course of the 1980s and 1990s. As increasing numbers of heterosexual people acquired the virus, the way in which images about people with AIDS were constructed in public dialogue became an issue that threatened to entrench further the view that gay men were to be blamed for HIV/AIDS. People who had acquired the virus through the blood supply or blood products (a condition generally referred to as ‘medically acquired AIDS’) or the wives or children of
bisexual men who had passed on HIV/AIDS, were generally depicted as the ‘innocent victims’ of the virus. A sharp division emerged between depictions of these ‘innocents’ and those who had acquired HIV/AIDS through sex or injecting drug use. Those who became infected with AIDS through homosexual sex or drug use were portrayed as people who had in some way ‘chosen’ to be infected with HIV/AIDS through their moral lapses. Discourse around ‘innocent’ versus ‘guilty’ people with AIDS revealed the way in which negative stereotypes about gay men contributed to knowledge about, and perceptions of, HIV/AIDS.

*Once you could find an innocent victim with HIV through blood then there was a great deal of concern. But I think it became quite apparent that if there was an innocent victim there had to be a guilty one – someone had to be blamed, to be guilty (Bowtell, 2005)*

The view that gay men and injecting drug users were somehow at fault for their HIV infection was expressed through a variety of forums. For instance, at the Third National Conference on HIV/AIDS held in 1988, Wilson Tuckey, the then opposition spokesperson on health, said in his address:

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76 Bill Bowtell interviewed by the author 28 May 2005.
AIDS is very much a disease that results from deliberate and possibly unnatural activity. You don’t catch AIDS, you let someone give it to you (Tuckey, 1988:739) \(^77\).

This statement led to a media response that gave free reign to homophobic talk-back radio and letters to the press. While this soon led to Tuckey being replaced in the shadow health portfolio, the issue continued to burn in the media. The following quotation from a *Sunday Times* opinion piece, written by Perth-based Radio announcer Howard Sattler, is indicative of the approach taken by a number of media outlets.

It is a case of, if the implication fits wear it. AIDS “victims”… who acquired the disease through homosexuality or intravenous drug use, are guilty of a dangerous act which they could have prevented. They also suffer from their own mistakes, unlike their medically acquired counterparts who were fatally misled by a health service they believed was beyond reproach (Sattler, 1991:39).

Deborah Lupton, in her analysis of Australian media reporting on HIV/AIDS, found that those who acquired HIV through sex or drug use were routinely represented as

\(^{77}\) Ironically the sentiment that “you don’t catch AIDS, you let someone give it to you” was later adopted by AIDS organisations, although obviously the intention was quite different. In the hands of the AIDS councils the idea that “you don’t catch AIDS, you let someone give it to you” is intended to remind people that they can take measures such as safer sex to prevent HIV/AIDS. In this context it is meant to empower individuals to take responsibly for their health.
having some level of choice about their infection with HIV/AIDS (or at least choice over the actions they took which led to the infection), unlike those who had acquired the virus ‘innocently’ (Lupton, 1993:232-234). ‘Choice’ became the basis for distinction between the innocent and non-innocent – even in cases where people had ‘chosen’ their actions before HIV/AIDS was known about. Of course, a moral assessment about the nature of such choices (that is, people had chosen to engage in acts considered morally reprehensible) was an ever-present subtext.

By the mid 1980s there were moves to seek compensation for people who had acquired HIV through the blood supply. Early in 1986, NACAIDS supported a proposal to allow no-fault compensation to be given to people with medically acquired AIDS. This proposal, however, met with resistance from the Health Minister who saw it as a dangerous precedent and feared people with other illnesses would follow suit. The move was also resisted by AIDS activists who opposed establishing a system where people’s eligibility to gain compensation was assessed on the basis of how HIV was acquired, rather than on the basis of need (Ballard, 1999:256). Continued lobbying by the Haemophilia Foundation of Australia (HFA) eventually led to a partial resolution of this issue, with the Federal Government providing a seeding grant for the HFA to establish a trust fund to which people with medically acquired HIV could apply for financial assistance (Sendziuk, 2003:49).

AIDS organisations were not necessarily opposed the idea of compensation. They were in fact supportive of a campaign push by the Haemophilia Foundation of Australia to hasten the process of setting up a trust fund. However, they rejected the implication that some people were more deserving of care and compensation than others. AIDS organisations argued that compensation should be administered on the basis of need, not according to the means by which an individual acquired the virus. The general political and public consensus had always tended toward the view that gay men

Footnote continued next page
The issue of compensation continued, however, as people with haemophilia took legal action against several medical institutions – the Commonwealth Serum Laboratories (CSL), Blood Transfusion Services and hospitals – as well as against individual doctors. It was a tough case to prove as people had to show they acquired HIV at a time when medical providers had reasonable knowledge of the possibility of contamination, but had failed to take action. In other words they had to establish that medical negligence had occurred. The first successful case of a man with haemophilia suing a hospital came in December 1990 when the Alfred Hospital in Melbourne was ordered to pay $870,000 damages, plus over $10 million in legal fees. This led to a massive push by the HFA and the mainstream press for governments to provide compensation rather than force people to endure such excessively expensive and traumatic legal proceedings (Sendziuk, 2003:49-52). In May 1991, the Western Australian government negotiated a package with 22 claimants, each of whom received up to $301,000. South Australia and Victoria negotiated similar settlements later that year (Sendziuk, 2003:52-53). The NSW Government was less forthcoming, ordering the Government Senate Standing Committee on Social Issues to open an inquiry into the issue of compensation who had acquired HIV through sex should not be eligible for any form of compensation (Ballard 1999:257).

Executive Director of the Haemophilia Foundation in the early 1990s, Jenny Ross, makes it clear that the Foundation was only ever seeking compensation for a medical procedure that caused harm and further illness. They never sought to demonstrate that people with haemophilia were ‘innocent’ victims of AIDS, or that any other groups were ‘guilty’. The media may have adopted such language, but this was not at the encouragement of the Haemophilia Foundation (Interview with Jennifer Ross, 1993, by Heather Rusden, for the National Library of Australia Oral History Project, The Australian Response to AIDS, TRC 2815/18).
(Hurley, 1992:412). The terms of the review were “to investigate and report on, as a matter of urgency”:

(a) whether patients who have contracted HIV infection through blood, or blood product, transfusion, or via artificial insemination from a donor, are receiving adequate and comprehensive health and welfare services:

(b) whether compensation should be paid by the Government to patients who have contracted HIV infection through blood, or blood product, transfusion, or via artificial insemination from a donor: and

(c) whether the decision regarding the suitability of blood and semen donors made by health authorities in 1983/84 was appropriate in light of the information available at the time regarding HIV infection (Parliament of NSW 1991).

Michael Hurley argues that the terms of reference for this inquiry (re)mobilised a conservative discourse around ‘innocent versus guilty victims’. ‘Mode of transmission’ was the central epidemiological category by which the inquiry would decide whether compensation was valid. According to Hurley, differentiating between modes of HIV transmission presumes that some people had greater knowledge, awareness or choice in the means by which they acquired AIDS than others. That is, it immediately created two categories of people with HIV – those who can ‘blame’ others for their HIV infection and those who can only ‘blame’ themselves. Through the inquiry it was suggested that gay men and injecting drug
users had an awareness of the possible health risks involved in their activities (even if they didn’t know about HIV, there were other risks) and could have withdrawn from them, whereas people who had acquired HIV through medically based procedures had no choice about the activity which resulted in their infection. For instance, Hurley refers to a submission that states: “Those people who were engaging in careless sexual activity and who were using intravenous drugs knew there were health hazards associated with that and freedom of choice was exercised in engaging in these activities” (Hurley, 1992:150). This suggests that, although most HIV positive people in NSW in 1991 acquired the virus before its existence was known, the fact that their actions posed potential health risks with regards to other diseases or complications meant they willingly placed themselves at greater risk of acquiring HIV (Hurley, 1992:151).

The category “mode of transmission” is socially mobilised as a medico-moral technology. This mobilisation joins other techniques in the creation of two quite separate HIV populations: the innocent and the guilty. Both populations are victims in the process, but one more so. The innocent victim is the quintessentially vulnerable victim, a victim both passive and pure. Gay men in this scenario are both guilty victim and monster (Hurley, 1992:153).

This media ‘beat up’ that occurred around the inquiry, including the media’s focus on AIDS activist’s resistance to compensation, also contributed to the presentation of gay men as acting selfishly in their response to HIV/AIDS (Hurley, 1992:148). This perception was given further merit when a member of the Senate Standing
Committee on Social Issues, conservative MLC Franca Arena, called a press conference in early August 1991 amid allegations that AIDS activists were planning to publicly 'out' her two sons as gay using a poster campaign. After Arena had been warned by a journalist about the alleged poster campaign, she attempted to undermine it with a public assertion that AIDS activists were malicious and intent on harming the reputations of her and her family. As it turned out, there was no evidence that a poster campaign had been planned and it never occurred\(^80\) (Hurley, 1992:142; McClelland, 1991:12). But the outcome of her press conference was a front-page headline in the *Sydney Morning Herald*: “Vicious Gay Campaign Against Franca Arena” (Hurley, 1992:142). The Sydney Morning also ran a feature article titled, “Gay Guerillas Come out to Prey” discussing the tactic, adopted at various times by some gay groups, of publicly ‘outing’ high profile individuals. The article argued that gay groups deliberately destroyed the lives and careers of public figures for their own selfish political agenda (Stapleton and McCarthy, 1991:36). The ethics of ‘outing’ is a topic of debate within the gay community and is by no means something all gay activists condone. But, regardless of opinion on this matter, the media portrayal of AIDS activists in relation to the Franca Arena controversy contributed to the construction of an image of gay men as morally questionable, as well as being at fault for their own illness.

The outcome of the NSW government inquiry appeared to be dissatisfaction on all sides. AIDS activists were frustrated with the outcome, arguing that the $10 million

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\(^{80}\) A poster campaign labeling Arena a ‘homophobe’ did later take place. AIDS activists accused her of homophobic conduct for arguing publicly that only ‘innocent victims’ deserved compensation.
allocated to compensating people who had acquired HIV though medical procedures should be used to assist all people with HIV/AIDS, or at least those most in need. Yet advocates for those with medically acquired AIDS were also upset about the relatively small individual payouts (which ranged from $5,000 to $50,000) (Hole 1991: 2).

Innocence and Discrimination

Heterosexual adults and children who acquired HIV/AIDS were treated differently in the media to gay men and the notion of ‘innocent victims’ perpetuated ideas that gay men were to blame for HIV/AIDS. ‘Innocence’ allowed non-homosexual people with HIV/AIDS to distance themselves from the stigma associated with gay men. This is not to say, however, that ‘innocent victims’ of HIV/AIDS did not also suffer fear or discrimination as a result of the virus. Indeed analysis of the way in which non-homosexual people with HIV/AIDS were treated by the mainstream community is a useful way to assess how much of the stigma associated with HIV/AIDS was related to homophobia and how much was fear of contagious disease.

Groups that had commonly been defined as ‘innocents victims’, such as people with haemophilia and children, were at times targets of AIDS hysteria as much as gay men were. For instance, Executive Director of the Haemophilia Foundation in the early 1990s, Jennifer Ross, recalls that many of their members requested that information from the Foundation be sent to them in unmarked envelopes. People feared that if others knew of their haemophilia they would assume they also had
AIDS. As Ross describes: "The fear is incredible" (Ross 1993)\(^81\). There were also some high-profile cases in which children infected with HIV/AIDS were victimised – perhaps the most notable being that of NSW toddler Eve Van Grafhorst

Eve van Grafhorst was born prematurely in July 1982. She underwent eleven blood transfusions to save her life. One of these transfusions infected her with HIV (Bagwell, 1985:8). When she was three years old, in 1985, Eve was banned from her kindergarten in the Kincumber area, North of Sydney, for supposedly presenting a risk to other children by being a ‘biter’. Eve had been banned from the centre once before this, but was allowed to return on the advice of a psychologist that she no longer presented a ‘biting’ risk. Parents of the centre, however, mounted a vocal protest and 40 of the 58 children who attended were withdrawn on the day Eve was scheduled to return (Editorial, 1985a:1). It was only two-weeks later that Eve was banned again for biting (Editorial, 1985b:6). Fears that Eve would spread HIV/AIDS to other children initiated what has been described as a ‘wave of media-fuelled public persecution’ against Eve and her family (Mark, 1993)\(^82\). Neighbours would spit at Eve in the street and some people moved house to get further away from her (Whelan, 1990:2). Eventually, following years of harassment, Eve and her family moved to New Zealand where she died from AIDS-related illnesses in 1993.


On Eve’s death, the Mayor of Gosford, responsible for governing the Kincumber area, said: “We should never treat anyone like pariahs or lepers but we found it pretty difficult for a while. She was a victim of a time, of a very sad time” (Sydney Morning Herald 1993:3). As this quotation suggests, AIDS related discrimination was a product of ‘AIDS hysteria’ and by no means exclusively directed toward gay men. However, unlike the discourse on AIDS and gay men, the persecution of Eve was followed by a sense of shame after the event. Press reports refer to Eve as a ‘teacher’ – as someone who taught people to be more compassionate toward those living with HIV/AIDS. The media focused on the guilt and sorrow felt by people involved in the persecution. For instance, a biography of Eve printed in the Sydney Morning Herald after she died stated:

Eve, who in her quiet way shamed Australia into admitting its ignorance and prejudice towards AIDS sufferers, was mourned by family and friends, politicians, and the community that chased her from her home eight years ago ... Councillor Dirk O’Connor, the Mayor of Gosford, the town which rejected Eve and later apologised for the way it treated her, said he was glad the Australian community had made its peace with Eve before she died (Sydney Morning Herald 1993: 3).

However, by 1993, the Australian public had certainly not accepted that ignorance and prejudice had been a feature of the community’s response toward all ‘AIDS sufferers’. In the same year of Eve’s death, Bill Mandle wrote in an opinion piece for the Canberra Times that stated:
We may rightly have sympathy for the miniscule number who suffer from accidental AIDS, the transfusion victims and those with inherited AIDS. One may have some, but less, sympathy for those heterosexuals who have had normal intercourse with ones who turn out to have been infected bisexuals. But why we should be persuaded to have any more than the normal meed of sympathy one has for the sick or criminal is beyond all reason – particularly if the sickness is self-inflicted and the criminality is a deliberately unlawful act taken with full cognisance of its illegality (Mandle, 1993:26).

In the case of Eve, and the many other tragic stories of HIV positive children being persecuted and prevented from attending school, the central issue was that the community feared these individual children would unintentionally pass on AIDS to their peers. In contrast, gay men as a group – regardless of their HIV status – were constructed as untrustworthy, deviant and blameworthy in the face of AIDS. There was a structural element to the discrimination of gay men that wasn’t present in relation to children. The notion of ‘irresponsibility’ was extended beyond individual sexual practices to encompass ‘gay lifestyles’. The entire gay community was seen to

83 There were some high profile cases in the United States where communities demanded that HIV positive children be removed from schools. In 1985 the Centre for Disease Control (CDC) published guidelines advocating school aged children with HIV/AIDS be allowed to attend public schools. Parents across the country reacted with anger, fearing the risk to their children. The issue became most heated in the case of Ryan White, a 13-year-old by who was infected with HIV/AIDS and had haemophilia, who was barred from school in Kokomo, Indiana in 1985. In another case, parents organised a boycott of schools in New York because the Board of Education had made a decision to admit one unnamed student with HIV/AIDS to an unnamed public school. On 9 September 1985 11,000 New York children did not attend school (Brier 2002:152). In Alabama 1987, the house of a family who had three sons, each of whom had haemophilia and was HIV positive, was torched following threats against the family warning them to keep their sons out of school (AVERT 2006).
be at fault for the spread of HIV and certainly no gay man was considered innocent (Gould, 2000:168).

Media Moves: Refiguring AIDS, Refiguring Gay

It is difficult to make any firm conclusions about how successful the AIDS movement was in challenging the social construction of ‘innocent’ versus ‘guilty’ people with AIDS. But this is perhaps one of the clearest examples of the way in which the AIDS movement consciously engaged with a ‘politics of knowledge’ around HIV/AIDS – deliberately seeking to break down the association between AIDS and deviance and the perception that some were more innocent than others.

Embedded in the philosophy of inclusion and respect was an adverse reaction to media stereotyping. So people put work into doing things like media guides and that sort of thing. So there has been an acute awareness that the way the media was reporting was accentuating stigma and limiting people’s quality of life (Rankin, 2004).

As Rankin suggests in the above quotation, activists were acutely aware of the potential for media stereotyping of gay men and people with AIDS, and took action to reorient the language used by media outlets in regards to people with AIDS. Most notably, they lobbied for the media to cease using the terms ‘innocent’ in relation to HIV/AIDS, encouraging them to either not make any reference at all to how a person acquired the virus or to use terms such as ‘medically acquired AIDS’ or other less

\[\text{84} \quad \text{Ian Rankin interviewed by the author 26 July 2004.}\]
AIDS being fed to the media was marked with the particular language and ideology of AIDS movement.

I clearly remember those debates around the board table at the Victorian AIDS Council. The propaganda battle ... wasn’t so much propaganda, but we had to manage through the media the potential for homophobia to severely get out of control. For example, when I was president of AFAO, every morning I would get into work at 8.30 ... and we’d go through all the newspapers looking for stories and by 9.30 we’d have a press release out. We didn’t have email then, we only had a fax machine, but we had this new system of polling the faxes out to a number of outlets. We couldn’t afford to go through a press agency, so we just polled it out to a number of major newspapers. We revamped the National AIDS Bulletin, so it was a much more glossy magazine. Adam Carr was writing the gay health update, every week or two weeks, put out the latest epidemiological update of AIDS around the world. That was incredibly informative. At that stage I was working at Fairfield Hospital in Melbourne and it was standard for Fairfield Staff to read the Gay Health Update to find out what was going on. That was their source of medical information (Plummer, 2004).86

As a result of its strong media campaigning, the AIDS movement developed the capacity to command media attention. As early as 1986, Phil Carswell, the then president of the VAC, noted:

86 David Plummer interviewed by the author on 30 August 2004.
You don’t often see AIDS talked about in the papers without a quote from someone in VAC. The media attitude has changed. We’ve tried to talk to the reporters and get them to understand the complexities of what they’re working on (Carswell, 1986:2).

Whether or not this media publicity led directly to a reduction in the ‘innocent’ ‘guilty’ divide is not clear. Activist, Ken Davis recalls that there was some questioning of what it meant to be ‘innocent’ when groups of heterosexual women, who had contracted the virus through sex with their husbands, came out and publicly questioned whether they were more ‘innocent’ than gay men given they had also acquired the virus through sex (Davis 2004). Deborah Lupton (1993), in her analysis of media reporting on HIV/AIDS, found that the media slowly came to demonstrate greater sympathy towards gay men living with HIV/AIDS. Over time there were an increasing number of articles in which the stories of individual gay men with AIDS were told and explicit expressions of prejudice started to lessen. Despite this, the fundamental division between people who had caught the virus through sex and those who had caught it through blood products retained its presence in media reports. Even where the term ‘innocent’ wasn’t used journalists continued to focus on the mode of HIV transmission – with reports about individuals living with HIV/AIDS invariably noting how the subject of the story had acquired the virus. The focus of such stories was often on how HIV positive gay men were atoning for their sins through educating others about HIV/AIDS or caring for people

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87 Ken Davis interviewed by the author on 4 November 2004.
who were ill. In contrast, people who had acquired HIV though blood transfusions or blood products were presented as deserving of compensation (Lupton 1993: 232).

Nevertheless, while media was central to its campaign, the AIDS movement did manage to engage the public in other ways. Education initiatives conducted by the AIDS Councils were well funded (through their partnership with the Federal Government as well as through their community fund-raising) and provided many opportunities for gay activists to connect face-to-face with the mainstream public.

Engaging the Public

In April 1987 the infamous ‘Grim Reaper’ television campaign hit Australian screens. The commercial depicted a cloaked ‘Death Reaper’ standing in a ten-pin bowling alley, set to bowl down a group of men, women and children. These images were so striking that nearly twenty years after the campaign ended, and despite the fact that the advertisements screened for less than three weeks, they can still be recalled in detail by wide sections of the population. The image of the Grim Reaper is often drawn on as a symbol of Australia’s response to AIDS in the 1980s (Sendziuk 2000:137).

The campaign had been initiated by NACAIDS, its main goal being to broadcast to the heterosexual community the message that everyone is vulnerable to HIV/AIDS, not just gay men (Vittelone, 2001:34). However, many AIDS activists were disappointed with the content of the Grim Reaper campaign (which had been approved by a subcommittee of NACAIDS that didn’t include the VAC or ACON representative), arguing that it negatively represented gay men. It was feared that
people would see the ‘Grim Reaper’ as symbolising gay men rather than HIV/AIDS thus reinforcing the notion that it was gay men who were responsible for AIDS deaths and not a virus. Also, information about HIV prevention was not included in the television commercial. Despite these misgivings, however, AIDS activists did recognise that the publicity around HIV/AIDS generated by the Grim Reaper campaign was an invaluable resource for them in terms of attracting public attention.

Being the first large-scale television promotion about HIV/AIDS, and the first major publicity campaign to suggest that heterosexual people were also at risk of catching the virus, it ignited a flurry of media and public hysteria. For AIDS organisations, it became an opportunity to massively increase their public profile, as the VAC president recalls:

_I didn’t see that ad before it came on television. It was a special subcommittee of NACAIDS who finally approved it. I remember Bill [Bowtell] ... told me that they were fighting over it until the last minute because of the opening words which were, I think: “At first we thought it was just homosexuals..”. Bill objected to ‘just’. It made it sound like it was ok if it was homosexuals. But now it’s for ‘you’, which implied that there was some sort of hierarchy of pain. And he recalls he actually spent a lot of time arguing that point, but got out-voted in the end. And it was a very tough decision, it was Ministerial level and Prime-Ministerial. I regret that in the ad. But I don’t regret what the ad provided for us in terms of an open door to every school in the country, and open door into every bowls club and social organisation and rotary in the country, every doctor, GP and health_
professional who tried to ignore it in the past now couldn’t (Carswell 2005b)\textsuperscript{88}.

To challenge the negative portrayal of gay men in the Grim Reaper commercial, and to take advantage of the intense upswing in public attention to AIDS, the VAC organised a counter campaign that involved running an advertisement on 10,000 milk cartons highlighting VAC initiatives and HIV/AIDS information\textsuperscript{89}. They also produced a free HIV/AIDS information booklet (Grant, 1987:12)\textsuperscript{90}.

In other states, the AIDS Councils were inundated with inquiries from the general public. For example, the AIDS Action Council (AAC) of the ACT took over 500 calls in the weeks following the Grim Reaper campaign, as its former coordinator recalls:

Most of the 537 calls we took were from the worried-well. This group is clearly not at risk, or is at low risk, but are concerned with some minor aspect of the AIDS phenomenon – hairdressers, mosquitoes, or more commonly, teenage daughters coming of sexual and independent age. They take a lot of time and patience to deal with, and it is tempting to leave them to their worries. But they are of course the landlords, business people, service providers, or simply colleagues, parents, children or siblings of people at risk.

\textsuperscript{88} Phil Carswell interviewed by the author on 23 July 2005.

\textsuperscript{89} Phil Carswell adds: “imagine the impact of those milk cartons around the family breakfast table.”

This is one example of the ‘reach’ that the AIDS movement had, influencing public consciousness way beyond the borders of the gay community (Carswell 2006).

\textsuperscript{90} Victorian AIDS Council Annual Report 1987
They are people who can provide – or withhold – services to our client groups – and like you they are potential AIDS educators (Westlund, forthcoming 2006).

AIDS activists also made face-to-face contact with many members of the broader, heterosexual community through care and support work. In the early 1980s, community volunteers provided virtually all home-care services for people who were ill with AIDS-related illnesses (mainstream services were reluctant to cater for people with AIDS). As most of these volunteers were gay men or lesbians, the volunteering side of the AIDS movement created many opportunities for gay people to connect with the mainstream public. Volunteer carers regularly met, and interacted with, the extended families of people ill with AIDS as well as their friends and neighbours. Also, as community-run volunteer services such as CSN and Ankali became more established, increasing numbers of heterosexual people volunteered, often because they had friends or associates that were connected in some way to the HIV/AIDS sector, or because they had known someone with AIDS. While these networks began within the gay community, they gradually expanded to bring increasing numbers of heterosexuals into personal contact with gay people and AIDS activists.

[People volunteered who weren’t part of the gay community] but there was normally a connection. I mean there had to be a connection ... But the connection was knowing someone who had been cared for, having a person who had been cared for, and then caring for others. So there were a lot of
relatives involved, whether it be the odd straight brother or cousin or sister, mother, father, grandmothers, great aunt, next door neighbour, it would often be that network, and that may even go into, or domino out, to that person’s network. There were people who got involved because they were somebody’s friend ... I trained up a group of people in Wollongong and we advertised for people to come and do this and I think there were two people who did the training who were not gay, both of them were involved in the Health Department, both of them knew me (not hugely well). Both of them had been involved in drug rehab work during their training and one of their closest friends was a gay man – he didn’t have AIDS, but he also did the training. So, yes there were other people involved, but the agency would not have survived [if it relied on] non-gay men (Crooks, 2005)\(^91\).

What I found was that as more and more cases were diagnosed and more and more people needed support – actual physical care teams – that there was this real osmotic effect out into the ’burbs and the bush. Families got to meet their first openly gay people. There was a real tectonic shift, or movement of understanding. For the first time I think families got to meet functioning, reasonable, nice gay men and women ... That helped break a lot of stereotypes. In the early days we used to have AIDS funerals where the biological family were out the front with the Priest not knowing what on earth he’s going to say because he doesn’t know the person he is burying, and these rows and rows up the back of wailing queens. And the biological family

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\(^{91}\) Levinia Crooks interviewed by the author on 28 January 2005.
would look at the 'family of choice' and say: "well who are you?" And we’d say: "Well who are you? We knew him better than you did." At some of these services, they were all cleaned up and it would be: "What are you talking about? That’s not the guy I knew" ... Eventually over time they became one. It took a while, and is still obviously not in all cases. I’ve never really heard it explored a lot, but I think that’s a really important theme – that we actually went out there into the 'burbs and into the homes and into people’s lounge rooms and nursed their sons in front of them – changed their nappies and cleaned up the vomit ... And actually provided a lot of emotional support for the family too. And I think that changed a lot of hearts in a lot of ways that is really unquantifiable, but was definitely there because from then on ... I think that was the precursor to the whole notion of why we suddenly have gay characters all over the TV screen, why we have 'Queer Eye for the Straight Guy'. There was that cultural shift that happened ... I don’t think any of us saw the silver lining that this big black cloud had and that’s the fact that many many many more people have now met a homosexual person (Carswell 2005b).92

HIV/AIDS also led to the creation of the first positions within the state and federal bureaucracies that were to be occupied by openly gay men. Most state governments adopted the Federal Government’s commitment to community-involvement in the Australian national HIV/AIDS response. Working within this framework, roles for gay community members were created within the new HIV/AIDS sections or groups

92 Phil Carswell interviewed by the author on 23 July 2005.
within some state health departments. Although gay people had certainly been employed by government agencies before this, and many had probably been quite open about their sexuality at work, this was the first time the state and federal governments deliberately and consciously hired gay people. The Victorian Health Department even ran a specialised training course for their staff to prepare them for a new ‘gay recruit’ – something that seems laughable by today’s norms, but is indicative of the lack of gay visibility within the public service in the early 1980s.

Phil Carswell was among the first group of people employed by the Victorian Health Department in its new AIDS branch. He recalls:

When I went to the Health Department in 1980 (whenever it was), I was told they had actually had a group set up for people who were working with me who had never known what a gay person did ... They seriously had a class ...

They were very cautious and on reflection I can see why they were. It was a cultural experience for them too and you can’t underestimate the fundamental nature of that change that took place. I think that was the most important part of the AIDS epidemic that has so far been undocumented ...

With all that going on, I think it sowed the seeds for a much deeper acceptance than there had been in the past. I think there’s been a tolerance in the past, but I think that there is now more acceptance (Carswell, 2005b)\(^9\).

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\(^9\) Phil Carswell interviewed by the author on 23 July 2005.
Personalising AIDS

Along with introducing more of the heterosexual public to gay men and lesbians, the AIDS movement was successful in publicly presenting a ‘personal face’ to HIV/AIDS. That is, rather than allowing information about HIV/AIDS to be presented to the public only in the form of statistics or ‘faceless’ information, activists ensured people living with HIV/AIDS had a public profile. This became a powerful political strategy, not only in terms of lobbying for political change, but with regards to reducing AIDS-related stigma. HIV positive activists visibly challenged stereotypes about what people with AIDS are like.

The People Living with AIDS (PLWA)\textsuperscript{94} movement began organising in the late 1980s. PLWA activists were a dynamic part of the broader AIDS movement and campaigned alongside other activists on a number of fronts. For example, in the mid-1980s they were heavily involved in a campaign to increase the number of beds allotted to HIV/AIDS patients in St Vincent’s Hospital in Sydney (Ariss 1989: 144). But PLWAs also played a distinct role within the AIDS movement by creating visibility for, and challenging negative stereotypes about, people with AIDS. As the former convener of PLWA NSW, Robert Ariss, once wrote:

All I can say is that such (media) work is essential if the debilitating image of ‘AIDS victim’ is to be challenged and our self-determination established and accepted, by ourselves and others. PLWA has a major role to play here, and I

\textsuperscript{94} Later to become People Living with HIV/AIDS (PLWA).
believe we have been very successful in increasing public understanding of
PLWAs in this state (Ariss 1989: 144).

Having people willing to publicly disclose their HIV status was at the heart of the
PLWA strategy. While for many people this was personally an incredibly
confronting thing to do for, it was a powerful strategy for the movement in terms of
eliciting empathy and creating a personal, compassionate connection between the
general public and people with AIDS – humanising the virus.

I think the shift [in public attitudes towards people with AIDS] happens early
on when people are prepared to stand up and say they're people with HIV. So
for me the shift actually occurs about 1987 with the beginning of the PLWHA
movement, as a movement of people standing up saying we've got HIV,
whether that's a gay man, whether that's a positive woman – being openly
known to be positive. That doesn't mean there's not discrimination, but that
marks the turning point ... In a way it's that kinda thing where you can't
'out' somebody if they're already out. That doesn't mean I say everybody
needs to be out, and there's a whole heap of reasons why you may not want
to be out (Crooks, 2005)\(^{95}\).

In terms of barriers, and this may just be my personal take on it, there
seemed to be a huge personal cost in becoming a public AIDS activist. It
usually meant disclosing your sexuality in a confronting way: often also

\(^{95}\) Levinia Crooks interviewed by the author on 28 January 2005.
disclosing your viral status in a confronting way. And even if this didn’t seem of great consequence to an individual if they were living in 2010\textsuperscript{96} or Prahran or wherever, it did have the ability to shock and confront the nation at large. People still took exception and were surprised in those days. So when you work that through the networks of families and all those networks that we exist in, the idea of doing that for the whole of your future, because you get marked out as a significant voice in a controversial issue ... People tend to remember, or people perceive that they are making life long commitments to that identity. I think we’ve seen during the ‘80s and ‘90s significant changes in the way people’s sexual identity is understood, lived and practised. Stuff we would have taken for granted as gay identity being a certain thing of a certain shape in the ’80s is perhaps in the 2000’s different (Rankin, 2004)\textsuperscript{97}.

PLWA developed a network of HIV positive people who were willing to speak publicly about their experiences. People from this network began to be invited to speak in schools and to community groups\textsuperscript{98}. Creating opportunities for people to actually meet someone with AIDS was a strategy designed to reduce the tendency for people to associate AIDS only with a particular ‘type of person’ (someone with

\textsuperscript{96}2010 is the postcode for Darlinghurst, an inner-city suburb of Sydney, with a high-profile gay community and a large number of gay businesses.

\textsuperscript{97}Ian Rankin interviewed by the author on 26 July 2004.

\textsuperscript{98}In NSW, the Positive Speakers Bureau was established as a formal organisation in 1994. It still operates today (http://www.plwha.org.au/PSB/). In Victoria a similar organisation exists, the PLWA Victorian Speakers Bureau (http://www.plwhavictoria.org.au/speakers.htm).
whom they would never interact) rather than a person who had a name and individual identity.

[In] ACON I was always wanting to do outward looking stuff, that assumed most of the people we needed to talk to weren't in the community. So we put up the [HIV positive] Speakers Bureau and that was as much for us as it was for them. Because it meant that we had to keep ‘retailing’ what we were thinking to these groups in the public ... So that was funny because it meant that people with HIV and gay men and other people that were volunteers had to negotiate all these immensely political questions on a daily basis with group of the public – schools rotary clubs, work places. And it meant that we had this ‘reality therapy’ all the time ... it got us out of that building ... So ‘retailing’ the story of AIDS to the public face-to-face, with feedback, was extremely useful. So we had a daily feel for what was in people's heads. Of course it was all a lot messier than anyone imagined. Of course there were people who had extremely hostile views and were very dismissive and were like: “it's a gay plot” and “why should they be treated specially” and “the government is conspiring with the gays to get a special deal”. But by and large that wasn't true, and as people more and more knew people with AIDS that really turned around. So by the end of the time we were doing that, I don't know when that was '93 or something, you'd go to a school and a girl would get up and say: “look my friend is on a combination of AZT [medication], or whatever, do you reckon it's worthwhile?” (Davis, 2004)99.

99 Ken Davis interviewed by the author on 4 November 2004.
Cultural Space to be Gay

While gay identities in general began to find a more prominent place in public life due to the AIDS movement, the nature of HIV/AIDS also gave activists an opportunity to direct public attention toward expressions of (homo)sexuality that previously had been very clandestine. This came about because HIV/AIDS created an imperative to initiate sexual health programs with groups or individuals that lacked visibility, even within the gay community itself. The Gay and Married Men’s Association (GAMMA) Project is one such example.

In Melbourne GAMMA had been operating as a small social support group for married gay men since the mid 1970s. In the mid 1980s ‘bisexual men’ were identified, for both political and epidemiological reasons, by the Federal Government as a key group to be targeted for HIV prevention education as these men, along with injecting drug users, were seen to be the ‘link’ by which HIV/AIDS could pass from the gay community to heterosexual people. An organisation such as GAMMA, which had existing networks with bisexual men, was an obvious group for the government to support financially. In 1986, GAMMA received a grant from NACAIDS to be used for HIV/AIDS education and research about the sexual practices of bisexual men, particularly those who were married to women while also regularly engaging in sex with men. The NACAIDS grant was the beginning of a much larger ‘GAMMA Project’ that was also extended to NSW (GAMMA 1986; GAMMA, undated publicity flyer). The first grant was for six months beginning July 1986. Funding was then continued and a national project, involving a telephone counselling service, was established (Tsitas, 1988: 6-7). Clearly without the imperative of HIV prevention,
the Federal Government would have been unlikely to support, or provide any legitimacy to, a group for men married to women who chose to have sex with other men outside their marriage. HIV/AIDS changed the scope of what was acknowledged publicly with regards to sexuality.

Gay and lesbian and youth were another group that gained greater public recognition in the wake of HIV/AIDS. Adolescence is often considered to be a time when people are developing their identities. Young people are seen to be in flux, moving toward their fully formed adult self. It is a common view that sexuality develops over the teenage years, and that young people are yet to reach full sexual understanding or maturity. As such, homosexuality is often not acknowledged among young people. It is frequently assumed that people can't be capable of defining themselves as gay or lesbian when they are still young, and if they do it is assumed to be a 'phase'. Moreover, social norms generally maintain the view that young people need to be safeguarded from sex, or any sense of their sexuality. Assertion of their homosexuality by a young person is associated with a loss of innocence (Griffin, 1993:162-166; Irvine, 1994:57).

HIV/AIDS brought with it a threat to the health and lives of young people who were engaging in homosexual sex. Community AIDS organisations responded to this by initiating campaigns and projects directly targeting young gay men. When such programs first began they incited widespread controversy. For instance, in 1990 the Victorian Government banned a poster and print-campaign that had been produced by the VAC's Youth Project Team. The poster targeted young men who were considering having sex with another man. The poster's slogan, written prominently
across the bottom of an image of two young men kissing, was ‘When you Say Yes, Say Yes to Safe Sex’. The poster also stated that homosexuality was natural and it encouraged young men to seek out support groups and people to talk to. Initially, TV Week magazine refused to publish a print-media version of the poster on the basis that it would offend their readership. The Victorian Shadow Health Minister, Marie Tehan, followed suit, calling for a ban on the ad and the withdrawal of funding to the VAC (McKenzie 1992:1-5). In a media Statement, Tehan stated that:

It is scandalous that state or commonwealth money should be spent on advertisements encouraging young people to engage in homosexual activity, with statements such as: “it’s natural and if you’re safe you’ll have a great time” (Tehan cited in Heath, 1990:6).

The Advertising Standards Council went on to recommend that no media outlets allow publication of the poster. In protest, a ‘Kiss-in’ was staged in Melbourne’s Bourke Street Mall on World AIDS Day, 1 December 1990. Organised and advertised by several AIDS Groups including the VAC and the AIDS Coalition to Unleash Power (ACT UP), the campaign message was ‘Kissing Doesn’t Kill: Greed and Indifference do” (ACTUP, 1990). The AIDS Councils adopted the stance that social support and self esteem were key factors in ensuring young people make informed choices about their sexual activities and sexual health. They pressed ahead with youth oriented ‘safe sex’ promotions despite public criticism.

Further controversy emerged in 1997 around two programs launched by the Western Australian AIDS Council (WACAIDS). The first was an anti-homophobia education
package for high schools. The second was a public campaign titled, 'Trust Your Feelings'. Targeting young gay men and lesbians, the aim of the 'Trust Your Feelings' campaign was suicide prevention. Its central strategy was public dissemination of a poster that had images of young lesbian and gay couples kissing on the cheek (MacDonald, 1997:11). Following media controversy the 'Trust Your Feelings' campaign was rejected for funding by the then Western Australian Family Services Minister, Judi Moylan. The basis for Moylan's argument was that it was “more of a recruitment campaign for lifestyle preferences” than a message for suicide prevention (MacDonald, 1997:11). The issue was controversial because people believed that adult homosexuals were deliberately seeking to influence the sexuality of youth, to 'recruit' them to the gay lifestyle. Arguments were run in the newspapers, such as the following:

It is of great concern to our community when these types of organisations actively promote their homosexual behaviour as an acceptable or alternative lifestyle to all impressionable teenagers in our schools (Croft, 1997:6).

I am concerned because it is a joint project for the WA AIDS Council and the Gay and Lesbian Counselling Service. They are not in a position to give a balanced view of behaviour toward homosexuality because both organisations endorse homosexual behaviour as an acceptable lifestyle for teenagers. They could make young, impressionable students quite vulnerable (Dawson and Dawson, 1997:6).
Although many of the AIDS Councils’ youth campaigns such as this became cloaked in negative publicity, the debates that were held on these issues also created public space in which ideas about the nature of both adult homosexuality and youth sexuality were discussed. By asserting the need for programs to protect young people from HIV, the AIDS movement introduced a new perception of gay and lesbian youth as mature, capable and, above all, likely to be sexually active. Moreover, AIDS activists had an opportunity to openly discuss and publicly refute the notion that gay men were interested in ‘recruiting’ young people to homosexuality. For instance, WACAIDS issued open statements arguing that it is not possible to ‘turn’ heterosexuals into homosexuals.

No parent or teacher should ever assume their child or student is heterosexual. Statistics show that at least five per cent of the population will develop a gay or lesbian identity. No amount of ‘promoting, encouraging or teaching’ can influence sexual orientation. There is, however, a separate need for responsible education, support and counselling for young homosexuals… (Pratt, 1997:13).

In many ways the evidence of rising HIV rates eventually muted public criticism of youth-oriented HIV prevention campaigns. The very possibility that young people could be at risk of HIV/AIDS became a legitimate argument for creating services that aimed to protect gay youth. Through such services, AIDS organisations began to craft a new public space for youth to express a gay and lesbian identity. They gave greater acknowledgement and visibility to gay and lesbian young people, as well as introducing discourse that was affirming of youth homosexuality. Additionally,
HIV/AIDS forced health and welfare professionals working with young people, as well as schools, to address homosexuality. This has led to a significant increase in support and services for gay youth over the past two decades (Griffin, 1993:177; Rumesberg, 2002:26). Increasingly public dialogue around young gay men and lesbians is couched in positive terms, rather than panic about sexual corruption or loss of innocence. For example, in 1998 the Western Australian Health Department released a report aimed at reducing the suicide rate in gay and lesbian youth. The report stated:

The existence of gay, lesbian and bisexual young people is often denied, ignored or treated with contempt by society, especially the media and the education system, so that there is little opportunity for them to recognise, take pride and act on their sexual identity (Kendell and Walker, 1998:57).

By opening a door for recognition of forms of sexuality that don’t necessarily sit easily in mainstream Australia, HIV/AIDS raised a challenge to existing knowledge about, and attitudes toward, sexuality. The changing status of gay and lesbian youth, demonstrated by evident shifts in public discourse on youth and homosexuality over the course of the AIDS epidemic, is evidence of this. Such shifts resulted from the organised action of the AIDS movement.

Certainly [public acceptance of homosexuality] was the aim, and ... this was quite clear at the beginning. If we’re going to deal with AIDS properly we have to destigmatise the groups. As long as they remain marginalised, no access to services, no recognition for partnerships and things like that, then
that sort of ghettoisation is exactly what favours the spread of disease and a whole range of other public health problems. So that was the aim and yes I think that did happen a bit. I think hopefully it made it easier for some younger people who found that there were ways of discussing things that were not possible to speak about prior to this (Plummer, 2004). 

Conclusion

In Australia since the 1980s, HIV/AIDS has become inextricably linked with homosexuality. As activist Adam Carr states: “Since the early 1980s, the gay experience has had AIDS as its cornerstone, a daily reference point, written indelibly into the culture. Everything gay men do is tangled up in AIDS” (cited in Wilmoth, 1990:8).

When gay men first began to engage with the issue of HIV/AIDS there were claims that they were untrustworthy or selfish, reflected in ideas such as the notion that gay men were likely to conspire to deliberately infect the blood supply with HIV. This reaction followed the historical trajectory of discrimination and negative attitudes toward gay men. HIV/AIDS didn’t create these ideas, they were old notions applied to a new situation. But paradoxically, this new situation also carried with it opportunities for gay activists to challenge and change long held public attitudes toward homosexuality.

100 David Plummer interviewed by the author on 30 August 2004
Through debates such as that around ‘innocent victims’, as well as those generated by controversy over gay youth and blood donation, ideas about the nature of homosexuality and the characters of gay men were publicly contested. AIDS created an opportunity for gay men to regularly appear in the media with intelligent, articulate arguments supporting both their perspective on HIV/AIDS and advocating the rights of gay men and lesbians. Activists presented a ‘personal face’ to both gay men and the AIDS crisis and there were many opportunities for gay activists to interact face-to-face with the general public. AIDS activists also fought for increased visibility of gay identities. Gay youth, for instance, gained greater acknowledgement and recognition within Australian society as a result of youth-oriented HIV prevention campaigns. The range of activities undertaken by the AIDS movement effectively turned around a situation that appeared to threaten the rights of gay men and lesbians into one in which new opportunities for social inclusion were founded. Arguably, through the HIV/AIDS crisis, gay men and women came to know unprecedented levels of community acceptance and public visibility. As Bill Bowtell put it:

Well it was remarkable ... The one thing I thought would happen in 83-84 would be the end of the gay stuff. I thought that whatever happened, you were basically fighting a retreat from Moscow. My view was, personally, that we might as well go down on the attack, we might as well just do the right thing, get the money – I could use all the politics I had to force the issue at the top, and get the money and go down ... particularly when you had Reagan and the beginning of this fundamentalist reaction that’s become so catastrophic in the United States over 20 years. I won’t even say it’s right wing because that
does a lot of unnecessary damage to people who are genuinely right wing ...
And that was the beginning of it in the '80s. And you could see this happening and you could say well this is going to sweep us from power. And I just thought the power of it would be so strong that we would just go under ... The fear, the homophobia, the reaction. I've always thought there would be a reaction to the '60s. And I thought in the '80s it would come. But it didn't ... we said “well we’ll just fight”. “We’ll just do the right thing.” But I would never have thought in fact the result of the fighting back, or the fight about this, things would become so dramatically different ... [Because] of HIV I think gay people and other marginalised groups in and around them staked a place in the sun and they won't be tossed ... The question you can ask is well was it worth having HIV to have that happen? The answer is no, it's not ...
It's a bit like World War II, it greatly advantaged the position of women – the war. But given the choice between oppression of women and World War II, what would you have had? It's a terrible question to ask. But social upheaval and these things have a habit of busting up very conservative social structures. So I think you can make that point. You never get a chance to choose between the liberation of women and World War II, you just make the point that it reconfigures things and power and visibility. And HIV and AIDS did that around the world (Bowtell, 2005)\textsuperscript{101}.

New social movement theorists focus on the cultural significance of social movements, positioning movements as struggling for symbolic capital, and claiming

\textsuperscript{101} Bill Bowtell interviewed by the author on 28 May 2005.
cultural space to express new forms of social identity or space to articulate new ideals (Canel, 1997; Fraser, 1998:141). Perhaps one of the most significant achievements of the AIDS movement was not its contribution to tangible outcomes such as policy change, but its influence on changing the cultural environment. The AIDS movement was able to introduce into mainstream consciousness new ideas about the nature of homosexuality and the role that gay people play within society.

Over time, activists gained confidence in their right to be publicly and politically recognised for their work in the AIDS sector. While the fear of AIDS, and the history of homophobic stigma and shame that hung over gay men and lesbians, was still part of what drove the movement, there was also a growing sense of political and social self-assurance among movement actors. This could be seen in the increasing expectation among activists that the gay community would be consulted by the media on matters concerning HIV/AIDS and that AIDS organisations could, and should, be given funding for their work.

Its prominent role in the AIDS sector, however, at times brought the AIDS movement into conflict with the medical profession. The notion that gay men could not contribute ‘objectively’ to decisions about HIV/AIDS policy tended to linger throughout the 1980s and into the 1990s and had an impact on debates about HIV/AIDS and public health policy. This will be explored further in the following chapter.
Chapter Five: Public Health and AIDS Activism

White and Willis argue that there were three core groups competing to "enforce their definition of the (HIV/AIDS) situation" (1992:127). The first of these groups was the 'inner-circle' of doctors, scientists and medical researchers working in the HIV/AIDS sector. The second, White and Willis describe as the 'dissenting enclave' – those non-government 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 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 (White and Willis, 1992:127; Kippax et al., 1991:41). Borrowing from White and Willis, this chapter looks at 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, 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 collaboration that occurred between these different social groups.
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’ (Sendziuk 2003:94). 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.

However, for many people in the gay community 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 Western Australian AIDS Councils at the time showed that gay men were reluctant to take an HIV test because they did not trust government guarantees about 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 (Bull et al., 1991:8). The following extract from the memoirs of an Australian man, David Menadue, describes well the tension brought about by an HIV test.
My doctor, David Bradford\textsuperscript{104}, 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

\textsuperscript{104} 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 (Carswell 2006).
years, might not embrace this news. This was about disease, infection and death. There was no telling how people would react (Extract from “Positive” by David Menadue 2003: 25).

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. As Lex Watson, president of ACON at the time, wrote in Outrage magazine:

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 (Watson, 1985:7).

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 far outweighed the research benefits of widescale 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

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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+\textsuperscript{105} 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 (Carswell, 1985:6).

Carswell went on to conclude that:

The 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 (Carswell, 1985:6)\textsuperscript{106}.

The line taken at the time by people like Carswell and the VAC was that gay men should be practising safe sex regardless of their antibody status (either to protect 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 which the AIDS movement should, in principle, advocate (Carswell, 1985:6).

\textsuperscript{105} HIV Antibody positive.

\textsuperscript{106} Both Phil Carswell and the VAC re-assessed their position on testing when anti-viral treatments became available and it was demonstrated that early diagnosis could improve health outcomes for people testing positive to HIV.
Apprehension about testing was indicative of the climate of fear HIV/AIDS 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 canceling appointments for testing or demanding their medical records be destroyed (McDonnell, 1985:13; Green, 1985:10). 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 (Watson cited in the Daily Telegraph, 14 January, Sanderson, 1985:5).

Recalling the fears his patients expressed to him, David Plummer, a physician and gay man, described:

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 it was only..., well 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] (Plummer, 2004).107

**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. Fears such as those described in the above quotation from David Plummer were understandable in that context.108

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107 David Plummer interviewed by the author on 30 August 2004.

108 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

Footnote continued next page
Such anxieties were eased to some extent by the introduction of anonymous testing systems such as name-coding (Bowtell, 2005a; Davis, 2004; Lowe, 2005). As Bill Bowtell recalls:

And of course 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 (Bowtell, 2005a).

110 Ken Davis interviewed by the author on 4 November 2004.
111 David Lowe interviewed by the author on 12 July 2005.
112 Bill Bowtell interviewed by the author on 28 May 2005.
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 a network of clinics which members of the gay community did, in general, trust. As David Lowe put it:

In terms of trust in confidential processes I think ... 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? ... I think the 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

113 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 2006).
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 (Lowe, 2005).114

As David 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 influence that AIDS activists had over the gay community as a whole meant that medical professionals could not afford to ignore them. If the AIDS movement was calling for people to not 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 this115, supporting the gay community in their rejection of compulsory notification legislation, there were other medical

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114 David Lowe interviewed by the author on 12 July 2005.
115 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.
professionals who continued to reject any involvement of the gay community in the medical or public health response to HIV/AIDS (Green, 1985:10).

Tension between the AIDS movement and the medical fraternity had been developing prior to the testing debate. When 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” (Frail, 1985:1). AIDS activists felt that this was a vast over-estimation. They accused the Task Force of scare-mongering in a cynical gesture aimed at directing government funds away from community organisations and toward 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 withdraw from 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 the annual Sydney Gay and Lesbian Mardi Gras116 (Bagwell and Leser, 1985:3). Watson went on to argue that much of

116 Closing bathhouses and canceling the Sydney Gay and Lesbian Mardi Gras was discussed by the AIDS Task Force and came quite close to being endorsed (Carswell 2006).
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: “If we are not able to address the scientific and medical problems without addressing the political problems, we won’t get anywhere” (Professor David Penington cited in Bagwell and Leser, 1985:3).

Penington represented a very traditional approach to public health and medicine, in which doctors assumed patient compliance, and were able to operate fairly autonomously. Understandably given his background and training, Penington was also convinced that clinically-based approaches to the containment of infectious diseases held the greatest scientific merit. He did not believe that education and community-participation should receive funding at the expense of such scientific intervention. Penington was certainly not alone in his views. With regards to public health, the tension between individuals such as Penington and the AIDS movement were reflective of the divisions between what could be termed ‘old public health’ and ‘new public health’. Penington’s views represented a commitment to the biomedical model of public health that had long been the basis of disease prevention in Australia. However, in the early 1980s there was an emerging body of thought on public health that was beginning to have influence in international forums. Commonly referred to as the ‘new public health’ this new body of thought lent some support to the arguments being made by AIDS activists.
‘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. For example, 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 public health 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. However, this perspective 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 and public health became an extension of the medical and pharmaceutical industries (Frohlich et al., 2001:777; Lupton, 1995:38; Brandt, 1997:29; White, 1996:35).

Implicitly, public health has been a consistent theme in Australia’s history. Being a water-locked continent has meant Australia had always been in a strong position to enforce quarantine regulations (not only in regards to human health but also to protect animal and plant species). Thus, there is a sense that Australia has greater capacity than other nations to insulate itself from diseases. When AIDS arrived in the 1980s there was already a legacy of successful infectious disease eradication in Australia. For instance, mass childhood immunisation throughout the 1940s and 1950s led to eradication of major diseases such as polio and tuberculosis from the
continent (Waldby et al., 1990:178). This history filters through Australian national identity – disease is associated with foreigners while Australia is seen as ‘safe’ and healthy.

Australia’s public health history meant that the Federal Government was predisposed to taking an active stance in response to disease control when AIDS arrived. This proved to be an important political opportunity for the AIDS movement – who reaped the financial benefits of Government action in funds for AIDS organisation. But it also meant that public health authorities were strongly committed to biomedically-oriented public health interventions such as vaccination and mass screening, which had been successful in circumventing other epidemics.

That being said, challenges to traditional public health approaches weren’t coming only from the AIDS movement. From the 1960s onward, 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 health care practices such as community-based care, physiotherapy and health promotion. As a result, the base of what was considered ‘credible’ medical intervention was broadening. Involvement of practitioners other than western medically trained doctors was becoming more acceptable in the health sector. The orientation toward 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.
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 (Bates and Linder-Pelz, 1990:103; Crichton, 1990:180-181; Woolcock, 1999:49).

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 their Health for All by 2000 campaign launched at their Alma-Ata conference in 1978 (Crichton, 1990:111). 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 (Crichton, 1990:111 and 132).

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 party 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 (Carter and O'Connor, 2003:26-28).

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 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 (Crichton, 1990:157). 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 sub-committee and a health advancement section was established within the Federal Department of Community Services and Health (Crichton, 1990:157). 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.

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 (Davis, 2004)\textsuperscript{117}. 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 health care decision making (Epstein, 1996:10). 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 (Kehoe, 1992:26; Epstein 1996: 6).

\textsuperscript{117} Ken Davis interviewed by the author on 4 November 2004.
However, in the early 1980s 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 (Altman, 1994:17). But at that time, neither government nor AIDS activists had 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 (Plummer and Irwin, 2003:4). 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. There certainly wasn't 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.

The trends toward empowering patients and questioning scientific expertise antedated the epidemic of the acquired immunodeficiency syndrome (AIDS). As early as the late 1960s, observers noted an increase in health care
organisation, provision, financial, and research ... Nevertheless, the entry of AIDS activists into the health care scene has added a jarring new dimension to what was previously a genteel dialogue between patient advocates and clinicians, researchers and policy makers (Wachter, 1996:25).

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 toward a community education model or a more traditional public health approach combining scientific research and clinical measures.

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. 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 (Ballard, 1992:135). The Federal Government were 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 (Sendziuk, 2003:110-111; Ballard, 1992:135). This gave the AIDS movement funds with which to create increasingly sophisticated HIV education materials and programs.
The Politics of Safer Sex

The catch-cri of “safe sex”\(^{118}\) that came to define the AIDS era was an invention largely attributed to gay community activists in America (Altman, 1994:5). Since the 1980s, the concept of safe sex has been adopted by health promotion agencies across the world and it continues to be a familiar, almost ubiquitous, expression in contemporary western culture.

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’ (Prestage, 2002:17; Ariss, 1997:41). Australian AIDS activists initiated safe sex education 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 carinii pneumonia (PCP) and other illnesses and symptoms now known to be associated with AIDS (AFAO, 1992:15). One of the first activities of the Victorian AIDS Action Committee’s (VAAC) education team was the *Fantom Frangers* (sic), a community theatre act where volunteers dressed in white ‘Fantom’\(^{119}\) 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 (VAC, 1993:6). The inaugural meeting of the

\(^{118}\) 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.

\(^{119}\) The original Phantom was a comic book super hero.
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 modeled on a leaflet produced by the American ‘Sisters of Perpetual Indulgence’ (Carswell, 2006)\(^{120}\). This was followed up in 1985 with a promotion developed around the slogan ‘You’ll Never Forget the Feeling (of safe sex)’\(^{121}\) (VAC, 1993:12). In describing the work of the AIDS Council of NSW, Ken Davis said:

> 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 [an American] 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 stuff. 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 (Davis, 2004)\(^{122}\).

\(^{120}\) Phil Carswell, personal communication with the author on 25 October 2006.

\(^{121}\) This was a parody of a television and print commercial for Sheridan sheets that was running at the time (Carswell 2006).

\(^{122}\) Ken Davis interviewed by the author on 4 November 2004.
The approach taken to education by AIDS organisations was, and still is, based on the notion of what has been termed ‘sex positive’. It deliberately sought to eroticise safe sex, using visually explicit images and commonly-used language: ‘fucking’ not ‘sexual intercourse’ (Sendziuk, 2003:113). 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 (ANCARD, 1998:24; Prestage, 2002:17). The campaign, titled ‘Rubba Me’, 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” (Waldby et al., 1990:181). 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 which enabled it to go ahead as planned, it did spark some controversy (ANCARD, 1998:24; AFAO, 1992:16; Carswell, 2005b123). 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 (Olszewski, 1985:13).

123 Phil Carswell interviewed by the author 25 July 2005.
However, AIDS activists 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 is has been deemed permissible only for gay men (who are already considered far from innocent in such matters)\textsuperscript{124} (Waldby et al., 1990:182). 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, videos, theatre, cartoons, cabarets, dance parties and ‘cruising cards’.

[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 (Dowssett, 1998:186).

The community education model adopted by the AIDS movement advocated empowerment and support of 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 grass-roots safe sex campaigns.

[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 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 (Whittaker, 2004)\(^\text{125}\).

The success of the community education strategy and the extent to which gay men have adopted regular safe sex practice is a widely contested issue. 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 (Margo, 1989:8; Warren, 1988:3; Ariss, 1997:42). Sexual Health clinics at the time also pointed to decreasing rates of anal gonorrhoea, possibly indicative of more regular use of condoms (Sendziuk, 2003:123). 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

\(^{125}\) Bill Whittaker interviewed by the author on 6 November 2004.
community interventions as the rate of new HIV transmissions started to drop before government money had been made available (Plummer and Irwin, 2003).

However, in the 1980s and early 1990s many members of the medical community (although 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 (Ariss, 1997:170-180). ‘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 critically important.

Making it Compulsory

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 government on scientific matters relating to HIV/AIDS and suggest how best to allocate funding for research, prevention and treatment. The committee was
were many who advocated mandatory testing as a sound basis for a public health strategy.

The idea of mandatory testing was picked up by the media with some commentators likening HIV testing to the compulsory chest x-rays used to screen for tuberculosis in the 1950s, arguing that as Australia had used compulsory medical screening before there could be no claims of discrimination by the gay community if it were adopted for AIDS.

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 (Barnard, The Age, 19 March 1985:19).

David Penington and others 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 (Sendziuk 2003: 96).

While mandatory, population-wide HIV screening in Australia was never on the Federal Government’s agenda (largely because the cost of such a venture would far outweigh the funds allocated to HIV/AIDS at the time) it couldn’t ignore the increasing attention being paid to the issue. In July 1986, Health Minister Blewett invited stakeholders – community activists, medical professionals and government – to attend a summit, with the aim of achieving some 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 (Ballard, 1992:144).

The outcomes of this forum did not entirely resolve the issue however. The possibility of compulsory testing lingered and often found its way back into public debate – including a few days after the summit when David Penington, despite having attended the summit, publicly promoted compulsory testing of ‘high-risk’ groups (Carswell 2006)\textsuperscript{126}. 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 the issue from a human rights perspective, pointing out that identifying ‘high risk’ behaviour was a highly subjective exercise. Following an intensive lobbying effort this section of the legislation was eventually dropped from the draft bill (Carr, 1987:7). 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 (McCauley, 1988:4).

\textsuperscript{126} Phil Carswell, personal communication with the author 25 October 2006.
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 where 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 87 per cent felt that all injecting drug users should be tested (Carney, 1988a:1). A follow up poll indicated that only nine per cent of respondents thought that HIV testing should be anonymous (Carney, 1988b:1; Pirrie, 1988:10).

**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 of some form of forced detainment\(^{127}\) (Ariss, 1997:170-180). By taking this stance, however, activists and

\(^{127}\) 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 minimalised through the quarantine of international naval and passenger ships arriving in Australian waters. Those suspected of harbouring the pathogen were sent to a Commonwealth Quarantine Station (Briscoe 1996). A series of sanatoria were established as prophylactic and curative centres for Tuberculosis (Smith 1996: 55, Chrichton 1990: 22). Quarantine of 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 it was never seriously considered as an option by the Federal Government as a wide scale strategy. However, the option of detaining and quarantining HIV positive individuals who “act in a malicious manner attempting to infect others” was raised by the Federal Government in their 1988 discussion paper on the national HIV/AIDS strategy (*The Courier Mail* 1989).

Cuba was the only country in the world to ever institute mandatory quarantine 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 may have been because conditions in the country became so poor following the collapse of the Soviet Union – their key international

Footnote continued next page

Perceptions on what ‘getting tough’ would involve invariably contained some form of legislative action to enforce public health action. The media regularly cited examples of legal measures that, in their view, demonstrated the way in which laws could be used to prevent the spread of HIV. For instance, 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 positive128 (Watchirs, 2002:15). The *NSW Crimes Act* was also amended to make it an offence for “maliciously causing or attempting to cause

financial supporter – that sanatoriums provided a better standard of care and living (Hansen 2003: 2875).

128 In NSW 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 2002:15).
another person to contract a grievous bodily disease, which includes HIV/AIDS” (Watchirs, 2002:16). 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. That is, if a person is a member of a ‘high risk’ group they are legally forbidden from donating blood.

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, a distinctive moral agenda often crept into the debates about their introduction. For instance, laws that criminalised blood donation by some groups were made in the context of concerns that gay men were deliberately infecting the blood supply. This rested on a belief that gay men were likely to be malicious, or at best irresponsible and not to be trusted. In his address to the Third National Conference on HIV/AIDS held in 1988, Wilson Tuckey, the then opposition spokesperson on health, argued that in the interest of public health people with HIV should not be afforded any anonymity or freedom. The message was that the public needed protection from HIV positive people.

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 Beale’s exposure to
yellow fever\textsuperscript{129}... We have little sympathy for those who maim or kill in acts of violence, no matter how unpremeditated they might be (Tuckey, 1988:740).

While Tuckey’s views are known for their extreme conservatism, sometimes bordering on the outrageous, this quotation is still indicative of statements that reasoned gay men did not have a right to sympathy or to protection of their civil rights with regards to HIV/AIDS. This argument was framed as an appropriately ‘tough’ approach to public health and 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.

David Penington upheld his public campaign for a ‘test and contain’ strategy throughout much of the 1980s, arguing that this was necessary as people didn’t always act responsibly with sex (Sendziuk, 2003:81). This view was sustained by the

\textsuperscript{129} 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.” (Disability Discrimination Bill 1992: Second Reading, 19 August 1992, Federal Parliament, Canberra, transcript available at www.aph.gov.au).
subtext that ‘the type of people who have AIDS’ can not be trusted to be responsible with sex. In other words, the association between HIV/AIDS and groups already considered morally irresponsible implicitly supported such a punitive approach. Penington’s position as Chair of the AIDS Task Force meant that, as far as the media were concerned, he was the leading medical expert in Australia on HIV/AIDS and his opinion received widespread public attention. While many other medical professionals felt that this approach was not appropriate in the case of HIV due to the nature of its transmission\textsuperscript{130}, the traditional biomedical model was still the framework against which all other HIV prevention measures were to be assessed. Test and contain had an element of ‘proof’ about it. It had been used in previous epidemics and Australia had a strong legacy of eradicating disease using such measures.

\textit{The resistance was remarkable. There was absolutely, [an] institutional resistance from the Department of Health. Quite famously the Chief Medical Officer at the time 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,}

\textsuperscript{130}Some doctors who sat on the Task Force, and who were practicing in clinics, also argued that criminal prosecution associated with AIDS, such as prosecution for reckless behaviour resulting in transmission of the virus, would discourage people from seeking testing (Sendziuk 2001).
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 (Bowtell, 2005a)\textsuperscript{131}.

Creating the “Gay Lobby”

Another common theme that arose in response to the AIDS movement was the notion that there was a ‘gay lobby’ intent on ensuring its own interests above those of the heterosexual public. This linked with the argument that AIDS activists were deliberately blocking traditional, and scientifically proven, public health measures in order to protect ‘homosexual rights’. For example, David Penington expressed concerns that ‘the advocacy of homosexual rights’ was preventing the effective monitoring of the virus through mass screening of HIV/AIDS risk groups (Browning, 1992:21). Professor Fred Hollows, a prominent eye surgeon, also commented in 1990 that he believed the ‘gay lobby’ had too much authority in

\textsuperscript{131} Bill Bowtell, senior advisor to the former Australian Minister for Health, Neal Blewett, interviewed by the author on 28 May 2005.
HIV/AIDS policy making. Hollows used the word ‘hijacked’ to explain the influence of the gay community over government decisions (Browning, 1992:15).

The ‘gay lobby’ was 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. For instance, in an essay critiquing the ‘gay lobby’ Bob Browning writes:

Government Health Strategy on AIDS is based fundamentally on gay cooperation in Safe Sex in return for official validation of ‘gay lifestyles’ and assistance in promoting the gay socio-political agenda. It is crucial therefore to assesses (sic) whether the ‘gay community’ will respond adequately to official education campaigns and appeals for socially responsible behaviour that will not damage others. Is such trust a sufficient basis on which to gamble public security against a deadly epidemic? (Browning, 1992:43).

Later in the article Browning also writes:

[The] ‘gay community’, of its nature, gives some observers little confidence in the self-discipline or social responsibility of all its members, up to one in four of whom have the potential to be fatally infectious to others (Browning, 1992:49).
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 people within the medical profession did not trust AIDS activists because they felt that gay men could not possibly be capable of making objective decisions about a disease that affected them directly. Dr David Plummer, a gay man and physician, recalled a story that indicated the attitudes of many doctors:

*I’ll give you an example: I went into the staff room 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* (Plummer, 2004){132}.

Demedicalisation of AIDS

The community/social model of HIV prevention came to be seen by some medical professionals as the ‘demedicalisation’ of AIDS: a move away from ‘real’ public

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{132} David Plummer interviewed by the author on 30 August 2004
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 in its prevention and management. In carrying out this role the doctor has a responsibility both to the individual and the community (Phillips, 1998:641).

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 (Barnett, 1989:38).

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 health care workers, Shepherd argued that 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 they would refuse admission and treatment to any HIV positive person (Dewsbury, 1989a:10). 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 they would not treat a man for heart surgery because he was HIV positive (Date, 1993)\textsuperscript{133}: 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 (Heary, 1989:7).

Shepherd’s concerns, however, were clearly not only the health of medical staff. For a start, the issue became embroiled in the tensions between the AMA and the Federal Government over the re-introduction of Medicare, a move the AMA vehemently opposed\textsuperscript{134}. As Blewett recalls: “(The AMA) was in full trade union mode, engaged in a battle with the government over Medicare” (Blewett, 2003:7; Bowtell, 2005a\textsuperscript{135}; Ballard, 1992:137; Misztal, 1990:195). But Shepherd was also convinced that HIV/AIDS policy had become captive to the ‘gay lobby’ leading to an over-

\textsuperscript{133} By 1993, when the case was heard in court, St Vincent’s admitted that the decision was made in the context of ignorance and fear of AIDS that was a reality at the time (Date 1993:5).

\textsuperscript{134} The system of state control over the health system set up by the ALP has long been a point of political contention in Australian history, with the Liberal party and doctors groups in opposition to ALP policy. When the ALP Federal Government lost office in 1949, the Australian wing of the British Medical Association worked closely with the Liberal government to reinstate a philanthropic-entrepreneurial medical system. This gave ‘medical entrepreneurs’ control over hospital and clinic services. It also suited the ideology of user-pays and ‘deservingness and choice’ being promoted by the Liberal party (Crichton 1990: 42). This system was not challenged until 1974 when the ALP was again in power. A system of universal health insurance, Medicare (formerly called Medibank), was proposed. The Australian Medical Association vehemently opposed Medicare, and a year later when the ALP was ousted from government the Medicare system was dropped (Gray 1991: 136-137).

\textsuperscript{135} Bill Bowtell interviewed by the author on 28 May 2005.
emphasis on non-medical solutions and the marginalisation of doctors from the AIDS sector (Dewsbury, 1989c:7; Sendziuk, 2003:102). 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. The *Sydney Morning Herald* reported Bruce Shepherd as saying: “the meeting was to redress the imbalance where AIDS was being treated politically and by legislation, but not scientifically” (Sampson, 1989:9).

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 re-assert autonomy and control of the medical profession.

Shepherd and McNicol were further frustrated by the Federal Government’s reluctance to support their call for mandatory testing of surgery patients. 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 ABC (Australian Broadcasting Corporation) for broadcasting McNicol’s suggestion

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136 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 1990:6, Sendziuk 2003: 103).
that he 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” (Dewsbury, 1989b:11).

The suggestion was, of course, that Blewett may have a conflict of interest, or be unduly influenced by the ‘gay lobby’, because he himself was homosexual (at the time Blewett was in a heterosexual marriage).137

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 (Plummer, 2004).138

137 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.

138 David Plummer interviewed by the author on 30 August 2004.
Comments from medical professionals criticising what they saw as the ‘hijacking’ of AIDS policy by the gay lobby were frequent. In particular, David Penington resisted allowing AIDS Councils to be represented on official government committees, arguing that because they were primarily concerned with ‘defending gay interests’ they were not capable of providing objective advice (Ballard, 1992:139). Blewett was regularly presented in media accounts as being overly sympathetic to the ‘gay interests’.

This caricature was given creditability by the frequent attacks on the policy by medical men, by proponents of old-style public health approaches, by conservative doctors with political axes to grind. It was given wings when a leading medical advisor to the Minister lent his authority to the case (Blewett, 2003:12).

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 (Misztal, 1990:204; Ballard, 1998: 125-130). As Dennis Altman has written:

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 (Altman, 1994:26).

Conclusion

Negative attitudes toward 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. In many ways it was these homophobic attitudes that promoted the AIDS movement’s critique of medical authorities and medical knowledge. For instance, the validity of HIV testing as a public health strategy was questioned by activists because they did not trust medical authorities to maintain confidentiality and to protect the civil rights of people who tested positive. In other words, it was because of prejudice against gay people that AIDS activists came to challenge medical authorities and to initiate a method of public health that explicitly rejected biomedically-oriented approaches. This chapter has demonstrated how, through their critical stance toward traditional public health measures such as wide scale testing, 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 is, 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 wasn’t based solely on medical knowledge. Instead, HIV prevention and health promotion was reframed as a community and political issue, not solely a medical and scientific problem. 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 World Health Organisation’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 World Health Organisation, as a ‘best practice’ public health model (AFAO, 1992:19). Despite foreboding criticisms at the time that ‘demedicalising’ the AIDS response could be disastrous, AIDS activists are now recognised for their role in the development of this model.

[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 (Whittaker, 2004)\textsuperscript{139}.

Confronting science and medical authorities did not necessarily 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. This, however, was not necessarily an easy process. Prior to HIV/AIDS, there had been no 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. The following chapter continues the discussion about the relationship between AIDS activists and the medical profession, looking at how these two groups came to trust each other, despite the AIDS movement presenting ongoing challenges to medical dominance.

\textsuperscript{139} Bill Whittaker interviewed by the author on 6 November 2004.
Chapter Six: 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 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, as Nick Crossley writes, “to enter into a relationship of dependency, compliance and cooperation in the service of getting well” (1998:509). Those who don’t 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 which regulate who can and can 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 capable of contributing to medical knowledge. That is, those who are not qualified according to orthodox western medical tradition – or not compliant with it – are given little authority to comment on ‘health issues’ considered by the medical profession to sit within its domain. This is not to suggest that this pattern of medical dominance is sustained through a conspiratorial arrangement, or that that individual doctors deliberately establish a relationship of dominance with their patients. Rather, it is to point to the history of western medicine in which the medical profession has sought to protect
and expand the boundaries around which it has control. This has largely occurred for material reasons, with the medical profession successfully marginalising other healing occupations in order to take over their client base. But also, the dominance of the medical professional has ensured the clinical and political autonomy of doctors. Rarely is medical advice questioned or contradicted by non-medically trained people. There is a sense that medical knowledge is not part of the ‘common pool’ of knowledge, but an elite and untouchable level of expertise that is beyond the critique of those outside the medical fraternity (Freidson, 1988:303; Emke, 1992:61; Germov, 2002:284; Alford, 1975:196; Epstein, 1996:7; Kelleher et al 1994: xii).

AIDS activists challenged this system of ‘medical dominance’ on two counts. Firstly, they refused to accept their allotted ‘sick role’: and secondly, they declared that their expertise, based on ‘inside’ community knowledge and personal experience, held as much authority in the AIDS sector as medical knowledge.

AIDS activists encouraged people living with HIV/AIDS to adopt a critical approach to their individual treatment regime, publishing comprehensive information about HIV/AIDS treatment options and encouraging community members to question their doctors about all clinical decisions. The AIDS movement also challenged medical dominance at a more systematic level though intervening in the process by which new HIV medications were clinically trialed and approved for distribution in Australia. The actions of the AIDS movement led to a major restructure of the drug regulatory system in Australia. The medical profession was also forced to negotiate
This chapter begins with a discussion of the emergence of ‘treatment action’, a new wave of AIDS activism that began when the first HIV anti-viral medication, AZT, was developed. I look at how ‘treatment action’ developed as a major focus of the AIDS movement and the implications that this had for the medical system in Australia – including the challenge the AIDS movement made to ‘medical dominance’ and the autonomy of the medical profession. I also look at how working relationships developed between activists and medical professionals, over time leading to greater involvement of lay people within the Australian health system.

The Beginning of Treatment Action: AZT

AZT (Azidothymidine or Zidovudine) was originally developed in the 1960s for the treatment of cancer. However in 1986, US researchers announced that AZT would begin to be trialed as a potential anti-viral 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’ (Sendziuk, 2003:210).

Large-scale clinical trials had been set up in the US to test for 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 (Ariss, 1997:167). Approval for AZT to move from the trial phase to general distribution in the US did not, however, translate into wide availability of the drug in Australia. AZT trials continued in Australia despite US authorities accepting that it was safe and effective.

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 US but not Australia was immensely frustrating for some people with HIV/AIDS. The following extract from the personal memoirs of a man whose lover was diagnosed with HIV in the early-1980s recalls this experience.

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 (extract 213...
When it became clear that it could be a long time before AZT would be widely available in Australia, frustration and anger became a driving force 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 only 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 around $10,000 (Ariss, 1997:168).

The issues raised by the AZT trial marked the beginning of the AIDS movement’s engagement with the pharmaceutical and medical systems 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) (Ariss, 1997:168). 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.

And I suppose 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 Anderson was still the 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 (Baxter, 1993).  

Medical Dominance and Treatment Action

Evan Willis describes the history of the Australian health system as one of competing tensions between occupational groups. Historically, western medical doctors have claimed dominance over ‘health issues’ in relation to other healing practices. Midwives, for examples, were once considered the primary ‘experts’ in relation to pregnancy and childbirth. However, in more recent history their role has become marginalised by obstetricians, who are generally viewed as more skilled in the area because of their medical qualification. The medical profession dictates the role that midwives can legally play in child birthing. This shift has not occurred because midwives are less capable of successfully delivering a child in the majority of circumstances than obstetricians: rather, it has been a process of one more powerful profession staking a claim over the occupational territory of another. The knowledge and experience of midwives is 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 (Willis, 1989:3 and 201).

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140 Don Baxter interviewed by James Waites on 26 November 1993 for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/75.
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 how to address health problems 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 (Wearing, 2004:276)\textsuperscript{141}. This is not to say that 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 history of the medical profession in relation to other groups, not necessarily because of the inherent nature of the knowledge they posses (Willis 1989: 3).

‘Lay people’ and non-medical authorities have been similarly locked out of the medical system – this was particularly so in the 1980s when notions of ‘consumer participation’ or ‘community involvement’ were not commonly accepted. Recalling her impression of the medical system in the 1980s, a former advisor to health Minister Neal Blewett, Kate Moore, writes:

\textsuperscript{141} I do not intend in this discussion to argue that obstetrics and modern medicine has not contributed to improving the safety of childbirth for both mother and infant. The point, rather, is that it is relatively recently that childbirth has come to be considered a medical process rather than 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 2004: 276).
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 (Moore 2006: 15).

In terms of the extent to which they ‘drew down the drawbridges’ of the medical establishment, the AIDS movement have 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 trialed 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. Firstly, activists wanted the government to fund the trials of new HIV therapies and to put more money into existing trials\(^{142}\). Secondly, they wanted the process by

\(^{142}\) For example, in early 1990, ACON began lobbying the government for greater commitment to testing DDI, a drug which was showing promising results in US trials – particularly for people who were intolerant to AZT (which could produce intense side effects) or for whom AZT was no longer working (Whittaker, 1990).
which drugs were 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 the medical research institutes and individual doctors involved in the trialing 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 by the outcomes of such trials.

**AIDS Knowledge, AIDS Action**

Although the AZT trials brought ‘treatment action’ to the forefront of AIDS activism, it wasn’t 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. Also, from the beginning of the 1980s activists had disseminated 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. That is, rather than waiting for health information to be provided to them from medical authorities, activists had taken charge of researching, producing and disseminating detailed clinical reports about HIV/AIDS. Activists did not see ‘medical knowledge’ as an area outside of
their domain. Not did they view medical authorities as having an inherent right to control such knowledge and information\textsuperscript{143}.

In July 1981, the gay community newspaper, the\textit{ Sydney Star Observer}, published a short article about cases of pneumonia that had been detected among gay men in the US (Ariss, 1997:77). 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\textit{ Campaign} magazine in April 1983 just after the first AIDS case 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 (Ariss, 1997:77; Misztal, 1990:199; Ballard, 1989:357; Plummer, 2004\textsuperscript{144}).

\begin{quote}
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 a 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
\end{quote}

\textsuperscript{143} 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 website \url{http://www.adam-carr.net/}.

\textsuperscript{144} David Plummer interviewed by the author on 30 August 2004.
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 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 (Carswell, 2005b)\textsuperscript{145}.

In the very early 1980s, AIDS activist also found themselves supplying information to general practitioners. At this point in time there were only small number of scientific publications on AIDS worldwide\textsuperscript{146}. 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.

\textit{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

\textsuperscript{145} Phil Carswell interviewed by the author on 23 July 2005.

\textsuperscript{146} See for example Marx, Jean L 1982 \textit{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} in \textit{Science} Vol 217, 13 Aug, pp 618-622.
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 (Plummer, 2004).147

When the first anti-viral 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 of shifting the power imbalance between doctors and patients. But also, 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 (Ariss, 1997:78). Alongside this, another treatment information magazine, Talkabout, began to be published in 1988 by the organisation People Living with HIV/AIDS (PLWHA) in NSW. Then, in the early 1990s, AFAO established a treatment information program with assistance from Federal Government funding.

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147 David Plummer interviewed by the author on 30 August 2004.
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 (Ariiss, 1997:80). AFAO also began work with the National Association of People With AIDS (NAPWA) to produce *Positive Living*, a publication which was first released in 1995 and quickly became one of the major sources of information about HIV treatments in Australia (Hurley, 2001:3). 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 may seem like an obvious initiative for activists to take in hindsight, there was not real precedent in Australia at the time of 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. As activist Ian Rankin observed:

> Some issues such 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 (Rankin, 2004).

**Coordinating Treatment Action**

Late in 1990, the Federal Minister for Health and Community Services, Brian Howe\(^{149}\), agreed to make AZT more widely available through clinical trials.

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\(^{148}\) Ian Rankin interviewed by the author on 26 July 2004.
Previously in Australia people had only been permitted to enter trials for AZT if their T-Cell/CD4\textsuperscript{150} cell count was less than 200. Following an ongoing campaign by activists, Howe changed the regulations to enable people with a cell count of less than 500 to access AZT trials, bringing Australia into line with the model being used in America at the time (Whittaker, 1990; Sendziuk, 2003:213). This allowed many more people to access AZT, but only if they were part of the trial.

In terms of making AZT available to people outside of clinical trials, there were two major delays. Firstly, 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 length of time the committee would take to process them (Whittaker, 1990). Wellcome finally delivered their submission with new data to ADEC on 31 May 1990. 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

\textsuperscript{149} Brian Howe replaced Neal Blewett as Federal Health Minister following the federal election in February 1990 in which the Australian Labor Party retained government.

\textsuperscript{150} 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 co-ordinates 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. People are considered asymptomatic if their T-cell/CD4 count is greater than or equal to 500 cells/mL (AVERT 2005).
priority issue. However, at the ADEC meeting on 26 June 1990, the submission was not even discussed (Whittaker, 1990).

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 Brian 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 able to (Woolcock, 1999:155).

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” (Ariss, 1997:186).

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, PLWA Victoria, VAC, PLWA Victoria, the AIDS Action Council of the ACT, PLWA ACT, 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” (ATAC, 1991b). They campaigned on a number of fronts, organising community protest 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” (ATAC, 1991a). ATAC also conducted street demonstrations and grassroots campaigns. At the 1991 Sydney Gay and Lesbian Mardi Gras parade, ATAC led a contingent of over 100 people dressed in black T-shirts adorned with a pair of red lips ingesting an AZT capsule (Ariss, 1997:189). ATAC were 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 (Andrews, 1991:1). 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 (Carswell 2006)\textsuperscript{151}. Also, in 1991, ACON established an AIDS Treatment Importing Scheme. This scheme exploited a 1990 amendment to the Australian Therapeutic Goods Act which 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

\begin{footnotesize}
\textsuperscript{151} Phil Carswell, personal communication with the author on 25 October 2006.
\end{footnotesize}
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) (Sendziuk, 2003:214).

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 anti-viral therapy. In the US, the treatment, called AL721\textsuperscript{152}, fell under the banner of an ‘alternative’ therapy. Following a campaign by US activists, AL721 had been made available as a food supplement rather than a pharmaceutical by the America FDA. 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 (Ariss, 1997:160).

The media campaigning that accompanied this was not always successful however. For example, a press release put out by the organisation People Living with AIDS

\textsuperscript{152} For more information on AL721 see Antonian, L, Shinitzky, M, Samuel, D & Lippa, A (1987) 
AL721, a Novel Membrane Fluidizer in Neuroscience and Biobehavioral Reviews, 11 (4), pp 399-413.
(PLWA) NSW in May 1989 asserted that clinics had a moral obligation to base their research priorities on community need and social responsibility (Ariss, 1997:160). The media did not respond to the press release as activists had hoped. Instead, the angle taken was that PLWAs were 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 (Ariss, 1997:183; Epstein, 1996:203). 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.

**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 playwrite 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 to each other, the organisation always remained resolutely 'grassroots' and informal with no centralised body and only limited formal structures (Woolcock, 1999:154). ACT UP was characterised by its distinctive form of cultural activism and use of symbols – the most prominent being the pink-triangle, reminiscent of the patch homosexuals were forced to wear by the Nazis during WWII, accompanied by the slogan SILENCE = DEATH (Epstein, 1996:220).
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 attracted people who sought a new, more militant, direction to their activism (Ariss, 1997:182). ACT UP also 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.

ACT UP’s first Australian street demonstration took place in April 1990. The protest was held outside the Commonwealth Health Department 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 (Brown, 1991). The demonstration received extensive television coverage, particularly 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 (Ariss, 1997:186).

The repercussions of that first demonstration were that ACT UP gained this tremendous self-esteem, you know, they ... I mean I think ACTUP’s breakthrough is that, whether or not ACTUP and AIDS issues are gay rights issues per se, they are often perceived as such, for any organisation which consisted mostly of gay-inspired... er... was gay driven, had never received that kind of publicity in Australia. And we had this breakthrough in that
ACTUP was getting regular mainstream publicity, and this was something new to a lot of activists to have that sort of success (Brown, 1992)\textsuperscript{153}.

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 (Woolcock, 1999:158).

\textit{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 ... Yabsley’s mandatory testing bill, and there was a big crisis in prisons happening at that time and all that sort of stuff (Brown, 1992)}\textsuperscript{154}.

One of the larger ACT UP protest was staged in Sydney in 1990 to coincide with the \textit{Sixth International Conference on AIDS}. The conference was being held in San Francisco and American chapters of ACT UP had organised a ‘take-over’ of the


main meeting hall (Ariss, 1997:186). Anticipating wide-scale international media attention HIV/AIDS because of the conference 'take-over', Australian chapters of ACT UP staged a co-current protest outside the American consulate in Sydney. This achieved high profile media attention.

(Like) many other ACTUPs 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 [the Immigration and Naturalization Service] enforces...[This] was really ACTUP's watershed, it was a kind of galvanizing thing where we really gained our reputation and our visibility (Brown, 1992).155

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 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 counter productive 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 (Woolcock, 1999:160; Goddard, 1993:17). 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 (Woolcock, 1999:155). 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 (Ariss, 1993:25-30).
Speaking about the Canberra chapter of ACT UP, activist Kenn Basham stated:

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
some thing we saw as a necessary, a legitimate part of our *Modus Operandi*
(Basham, forthcoming:263).

ACT UP never became as large in Australia as it was in the US. But despite its small numbers, ACT UP achieved a strong presence and their militancy and visibility did have the capacity to intimidate health ministers. They were also clever activists who, along with their street-protest, would compile comprehensive and well-researched media kits and campaign information.

*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 (Carswell, 2005).

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 twenty 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 (Sendziuk, 2003:211).

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 trials process and gain TGA approval. The TGA, with their stringent testing regimes, were 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) (Carr, 1992:22). 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 many years and required

156 Phil Carswell interviewed by the author on 23 July 2005.
significant financial investment from pharmaceutical manufacturers. In the 1980s, the average time between application and approval of a drug in Australia was around two and a half years (Carr, 1992:22; Sendziuk, 2003:214).

Communication between AIDS activists in Australia and those in the US meant people in Australia were well aware of the availability and efficacy of AZT. For Australian activists, there didn’t 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\(^{157}\) (Carr, 1992:22).

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 on 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 which manufacturers had to follow in order for new pharmaceutical products to be approved was overly slow and cumbersome (Carr, 1992:22). But also, perhaps more significantly, ANCA

\(^{157}\) In the USA, before HIV/AIDS campaigns were successful in changing regulations, it took on average twelve years to gain FDA approval for new drugs and cost the sponsor around 231 million US dollars (Young 1995: 53).
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 (Power 2006)\textsuperscript{158}. 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 centered on an ultimatum delivered to Howe to increase funding for drug trials and ease restrictions on pharmaceutical approvals before a set date, the allotted D-Day – 6 June 1991 (Carr, 1991:44). 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 implemented the demanded changes. 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 (Woolcock, 1999:157). 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 at 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

\textsuperscript{158} Prue Power interviewed by the author on 25 May 2004.
Parliament House by security guards they lit orange flares and staged a ‘die-in’ on the front concourse (Brown, 1991; anonymous, 1991; McDougall, 1991:1). 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’ (McDougall, 1991:1). 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 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 (D-Day Media Briefing Kit, ACTUP, 1991).

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 (ACTUP, 1990). The media kit argued that the Government needed to
account for the fact that a small population made Australia a relatively insignificant market for large pharmaceutical companies, as such there needed to be incentives for companies to submit their products to the Australian approval process (ACTUP, 1990).

(One) of the strong points about ACTUP 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 ACTUP'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 (Brown, 1992).\textsuperscript{159}

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 (Altman, 1992:60). The second review was headed by Peter Baume, a professor of community medicine at the University of NSW and former (Liberal) Federal Health Minister. Its findings were released in July 1991.

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, timeframe for approvals to which the TGA would be compelled to adhere (Goddard, 1991:1). Shortly after the report was released Minister Howe announced that he would implement all of Baume recommendations. Both activists and many members of the medical profession welcomed Baume’s approach to the problem.

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 one 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 Krohn’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)\textsuperscript{160}.

[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 good way around (Power, 2004)\textsuperscript{161}.

\textsuperscript{160} 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.

\textsuperscript{161} Prue Power interviewed by the author on 25 May 2004.
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 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.

[There] had been eleven 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 (Whittaker, 2004)\(^\text{162}\).

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

\(^{162}\) Bill Whittaker interviewed by the author on 6 November 2004.
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 (Whittaker, 2004).163

163 Bill Whittaker interviewed by the author on 6 November 2004.
Many 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 (Whittaker, 1991).

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 (Tony Keenan, VAC President 1992:4).

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. However, AIDS activists also 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. But also activists had began to challenge the authority of doctors and medical researchers who were running clinical trials.

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, *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 (Menadue, 2003:14; Woolcock, 1999:117; McQuarrie, 1993:7). 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 living with the virus.
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 US and advocated, as a political strategy, HIV positive people ‘coming-out’ and publicly declaring their HIV status (Ariss, 1997:138). 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 (Duffin, 1993:20; McCallum, 2003:32). 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 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 (Duffin, 1993:20).

The US ‘empowerment movement’ for people with AIDS established a set of principles to guide 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 – common terms in media and public 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 (Ariss 1997: 136).

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 (Ariss, 1997:148).

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 looks at the
health, lifestyle, safe sex practices, utilisation of services and treatment uptake of people living with HIV/AIDS. The survey has been repeated on several occasions since the first one to develop into a longitudinal study. As Hurley describes:

*Futures* provides the key research on the health and wellbeing of people living with HIV in Australia and is used extensively by NAPWA, state PLWHA organisations and service providers in policy and program development and in lobbying and advocacy ... People with HIV have had a long term impact on what is researched, how it is researched and how the research is used. It is read and listened to by federal and state health ministers, public servants and service providers (Hurley, 2003:39-40).

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 anti-viral medications\(^\text{164}\). 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 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 also lobbied for increased involvement of people with

\(^{164}\) In 1996 Highly Active AntiRetroviral Therapy (HAART) was introduced. HAART involves the use of several anti-viral medications in combination. The rate of mortality and morbidity associated with AIDS dropped dramatically with the introduction of HAART (Stewart 1988).
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 (Canavan, 2003:27-28).

As Canavan outlines, the position of NAPWA was that the personal experiences and opinions of HIV positive people was 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.

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 wasn’t 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.
The issue of the ethics of [randomised control trials] 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 (Rankin, 2004).165

As noted above, one major issue which 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. 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 (ACTUP, 1990). Activists threatened to undermine the validity of some placebo based trials by having their pills tested to see if they were active or placebo. Those with active doses would halve theirs in

165 Ian Rankin interviewed by the author on 26 July 2004.
166 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 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 may 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 (Willis 1989: 215: Epstein 1996: 196-197).
order to share it with people on the placebo pills (Baume, 1992). Through actions such as this, or the refusal of large numbers of people with AIDS to participate, 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. 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 (Canavan, 2003:27).

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

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167 Professor Peter Baume interviewed by Dr John Ballard for the National Library of Australia Oral History Project, the Australian Response to AIDS, TRC – 2815/1.
relationship between researchers and community is Australia is I think, amazingly healthy (Kaldor, 2003:32)\(^{168}\).

The ‘treatment action’ campaigning of the AIDS movement forced activists and medical professions began to work 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 and making through to working with pharmaceutical companies (Canavan 2004: 18-19). 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 commonly attributed to the work of the AIDS movement. (Whittaker 2004\(^{169}\)).

The combination of media portrayal of ‘AIDS victims’ together with a paternalistic and highly technological medical system were powerful forces against seeing people with AIDS as active agents in control of their lives.

The battle fought by people living with AIDS has revolutionised the

\(^{168}\) Professor John Kaldor, PhD, is Deputy Director and Professor of Epidemiology of the National Centre in HIV Epidemiology and Clinical 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.

\(^{169}\) Bill Whittaker interviewed by the author on 5 November 2004.
relationship between the medical system and a group of erstwhile ‘patients’ (VAC, 1993:3).

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” (1994: 18). 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. Some doctors, for instance, 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. 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:

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?” (Anonymous, 2005)\textsuperscript{170}. 

I think in the medical system we’ve never had, the orthodox medical system had 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 a 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 (Anonymous, 2005)\textsuperscript{171}. 

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

\textsuperscript{170} 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.

\textsuperscript{171} 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.
medical discussion. Activists had deliberately 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’.

*People like Don Baxter and Bill Whittaker (from ACON and AFAO) on these things became every bit as scientifically literate as the scientists and clinicians they were dealing with. Scientists and clinicians dealing with these trials and so on would be speaking to someone like Bill Whittaker or Don Baxter completely as equals. Baxter and Whittaker could deliver their group and these people could deliver the trials and the drug ... They needed each other. But they were dealing in the same currency so it was really quite exciting. I mean Don Baxter or Bill Whittaker if they'd wanted to could have gone on to do PhDs in the sciences and there were a lot of gay guys who were researchers and so on and over time their expertise went into the government, into the health department, into research, into the political representative side of it. So the gay side of it was remarkable (Bowtell, 2005)*.\(^{172}\)

\(^{172}\) Bill Bowtell interviewed by the author on 28 May 2005.
On this basis, AIDS movement ushered in a new set of expectations. The medical profession in Australia was forced to confront their reluctance to engage professionally with lay people. As one medical doctor stated:

*I think 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* (Anonymous, 2005)\(^{173}\).

Activists also had to learn to work productively within the medical system and institutions to which they had demanded entry. To achieve this, there were a number of instances where mutual goals between some sections of the medical profession and activists were exploited. For instance, general practitioners supported AIDS activists to lobby for faster approval of AZT. As long as AZT prescriptions were only available within a clinical trial, GPs were limited in the treatment options they could offer and locked out of the ‘loop’ in terms of HIV treatment. So, in part for

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\(^{173}\) This quotation is taken from an interview conducted by the author in early 2005 with a medical practitioner who was working in the AIDS sector during the 1980s.
their own interests, GPs often lobbied in support of activists (Ariss, 1997:75). Also, doctors and activists came to rely on support from each other to attract funding into the HIV sector.

[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 (Whittaker, 2004)\(^\text{174}\).

[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:

\(^{174}\) Bill Whittaker interviewed by the author on 6 November 2004.
"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 (Crooks, 2005).\textsuperscript{175}

**Drawing on Alliances**

The increasing alliance between AIDS activists and the medical profession demonstrates the way in which AIDS activists challenged the dominance of the medical profession, not only through political contest, but through finding ways to participate, as lay people, in the health system. That is, the professional boundaries of the medical establishment were impinged upon by activists, not only through overt political contest, but through their participation in the health system.

Brown et al (2004) refer to health social movements as ‘boundary crossers’. 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,

\textsuperscript{175} Levinia Crooks interviewed by the author on 28 January 2005.
collaborating with the ‘opposition’ and adopting an ‘expert’ identity of their own (Brown et al., 2004:64). 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 their ‘targets’ or 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. Breaking down the strong professional boundaries around the medical profession, however, means that inclusion of lay people is in itself a challenge to the existing social order. Collaboration between activists and doctors is, in this sense, is a radical maneuver (Brown et al., 2004:64).

The other important feature of the relationship between AIDS activists and medical researchers was the fact that many people stood on both sides of the fence. There were a number of gay men who were also doctors. These doctors had understandably become involved in the AIDS sector because HIV/AIDS was a medical issue to which they had very personal connections (Lowe, 2005)\textsuperscript{176}.

\textit{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}

\textsuperscript{176} David Lowe interviewed by the author on 12 July 2005.
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 (Plummer, 2004)\textsuperscript{177}.

The boundaries of any profession are determined by who is allowed 'in' and who isn't. 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 (borrowing from Fleck) terms the 'thought collective' of medicine (Shapin, 1994:7). The thought collective is a 'fund of knowledge' from which individuals draw and 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. 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

\textsuperscript{177} David Plummer interviewed by the author on 30 August 2004.
collective is legitimate in terms of the expectations of the medical profession. As Shapin describes:

Accordingly, 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 (Shapin, 1994:7).

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. That is, gay doctors gave activists an ‘in’ to the medical establishment and provided a more legitimate basis from which activists could contribute to medical knowledge. That is, 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. In this sense ‘gay doctors’ played an immensely important role in establishing relations of trust between the medical profession and AIDS activists.

Conclusion

Robert Ariss argues that the development of working relationships between doctors and activists was not necessarily an example of ‘relationship building’ between these two groups. Rather, doctor-activist partnerships simply served the function of rescuing “science from the threat of non-compliance” (Ariss, 1997:199). However, the threat of non-compliance was an important challenge to medical dominance.
Even if the ultimate priority of doctors and scientists was to maintain the scientific integrity of their research, the AIDS movement did force the medical system as a whole to change their processes.

AIDS activism has transformed the practices of clinical science from one that prioritises the demands of science itself, to one that is more responsive to the needs of human beings (Ariss, 1997:200)

Medical knowledge has a cultural authority rarely challenged. The autonomy and status of the medical profession is engrained in the modern social order and the capacity or credibility of doctors is not generally questioned. The common social order will generally only be brought into question when something occurs to change the way in which people live their lives – forcing them to confront the social structures that pattern their everyday existence. HIV/AIDS was one such occurrence.

The social history of homosexuality meant that gay men were less likely to trust medical science than other social groups may 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 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 (Misztal, 1996:131; Kimsma, 1990:50).

The medical profession maintains its dominance, not just because of the nature of medical intervention, but because the community has traditionally accepted and trusted the claims of medical professionals, not questioning their capacity or legitimacy. If the community (for whatever reason) ceased to accept the expertise and authority of western medicine, existing relations between doctors and lay people would break down (Daniel, 1998:217; Epstein, 1996:17). There is a strong argument that AIDS activists' mistrust of doctors and of science was highly important in determining the course of the AIDS movement\(^\text{178}\). Two key strategies adopted by the AIDS movement throughout its treatment action campaigns were: one, to assert an alternative basis of expertise, grounded in personal experience and community need, which challenged the autonomy of medical intervention: and two, to ensure activists gained enough technical knowledge about the physiology of AIDS and the processes of clinical trials to engage effectively in medical dialogue. In other words, 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.

\(^{178}\) 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 a mistrust of the mainstream, it has meant that the gay community has developed their own facilities. In the 1980s this included a network of gay-friendly GPs (Carswell 2006).
By the 1990s the AIDS movement had developed confidence in their capacity as ‘AIDS experts’. They had also achieved a certain level of credibility and legitimacy within the AIDS sector. They were formally recognised and funded by the federal and state governments and had an established media presence on HIV/AIDS matters. Their alternative, community-based model of disease prevention had also gained recognition and acceptance by public health and medical officials as well as government. As such the AIDS movement was in a position to challenge the notion that medical knowledge was the only form of legitimate knowledge about HIV/AIDS and, indeed, about the way in which clinical trials are conducted.

To challenge biomedical authority – whose meanings are part of powerful and deeply entrenched social and historical codes – has required considerable tenacity and courage from people dependent in the AIDS crisis upon science and medicine for protection, care, and the possibility of a cure (Treichler, 1988:40).

The AIDS movement demonstrated that the development of alternative forms of expertise (in this case an expertise based on personal experience and ‘felt knowledge’) has radical potential. A movement, representing people with an historically stigmatised and marginalised social position, cracking some of the boundaries that support a long established, powerful profession represented a significant structural shift. It wasn’t just a question of the movement achieving their intended policy outcomes (which they of course did as well) but of effecting a
change in cultural processes. This case study suggests that what movements achieve is much broader than that which can be measured in any quantitative sense. Often it may be their contribution to the production of social knowledge – ‘what we know’ about the world – that is their more significant legacy.
Chapter Seven: Rites of Belonging, the AIDS Memorial Quilt

The past two chapters outlined how the AIDS movement interrupted the traditional approach of western medicine to public health. The movement successfully gained legitimacy for their form of ‘lay expertise’, challenging the notion that medical issues can only be understood through the discourse of medical science. Knowledge about HIV/AIDS and related public health policy was produced through interactions between activists, the medical profession and the state.

Earlier chapters of the thesis discussed the role of the AIDS movement in recasting public perceptions of gay men. The AIDS crisis provided opportunities for activists to contest and rebuild long held assumptions about the nature of homosexual men. This chapter returns to this theme, looking at the AIDS Memorial Quilt and the annual Candlelight Memorials (also often called the Candlelight Vigils) held in Australia. I argue that these memorials challenged the stigma surrounding HIV/AIDS through creating public space for the expression of grief. The Quilt Project and Candlelight Memorials weren’t strategies aimed at achieving direct political or policy change. Rather, through paying tribute to people who had died from AIDS, and respectfully acknowledging those grieving for them, the Quilt Project and Candlelight Memorials expressed the social and political ideals of the AIDS movement and were an important form of cultural protest.

Memorialising AIDS in Australia

Each year in Australia, and throughout the western world, Candlelight Memorials are held in remembrance of people who have died from AIDS. Inaugurated in this
country by HIV/AIDS activist Phil Carswell and a nurse at the Melbourne Communicable Diseases Centre, Tom Carter, the first Australian vigil was held in 1985 when these two men stood silently with lit candles in a Melbourne city square. From this, the event grew in magnitude and scope. Ten years later, the estimated attendance at Candlelight Memorials across the country had grown into the tens of thousands and they were regularly attended by public figures such as the Health Minister and the Human Rights Commissioner. Candlelight Memorials involve a silent procession and vigil – held in the evening with thousands of lit candles – and a public reading of a list of names of people who have died from AIDS. They are often accompanied by the unfolding of new panels of the AIDS Memorial Quilt.

When new panels are revealed, this is the most moving thing. One time there were 15 people walking out with their panel all crying, sometimes it is the mums and dads, sometimes lovers handing over the panel. It is the most emotional, moving event. It is the epidemic happening (growing) in front of our eyes. Apart from someone dying, which most people outside the gay community don’t see, all the news stories and articles are lifeless. The Quilt makes it real. It has a heartbeat (Carswell, 2005a).¹⁷⁹

The visual and emotional impact of the AIDS Memorial Quilt is difficult to capture in written description. The Quilt itself is a series of cloth panels, each produced in memory of a person or persons who has died from AIDS, stitched together in the format of a traditional ‘comfort quilt’. When laid side by side the Quilt can carpet

¹⁷⁹ Phil Carswell interviewed by the author on 17 December 2005
literally hundreds of square metres. Each panel is 6x3 feet in size, deliberately the average dimensions of a grave plot – the size of a human body. The panels are sewn together in groups of eight. The first Australian AIDS Memorial Quilt was launched in Sydney on World AIDS Day in December 1988 by well-known media personality, and former NACAIDS Chairperson, Ita Buttrose. When it was first launched there were 35 panels. Today there are well over 700 and the Quilt Project is a registered charity with branches in most states and territories (Project, 2004).

Each panel is produced by the family, partners, friends or carers of people who have died from AIDS. Personal items are often stitched into the panels – old theatre tickets, favourite T-shirts, soft toys, photographs, jewellery. The ‘Quilt Project’ holds regular workshops at which volunteers assist people with the technicalities of producing their panel. Many panels include personal statements about, and dedications to, those who have died:

*I could read it quite clearly in his palm. There would be a terrible tragedy.*

*My love could not protect him, DM.*

*(He) loved the Australian lifesavers, the Iron Man competitions and the world’s most beautiful, yet dangerous, beaches.*

*Mr Cha Cha Heels. Teardrops on the dance floor.*
The Quilt invites its viewers to wonder about those to whom each panel is dedicated. The details of the textiles, the images, words and personal objects provide enough of a glimpse into the life of an individual to lead one to reflect further about who they were and how they lived their lives. In this way, the Quilt is both memorial and storyteller. As formed coordinator of the Quilt Project, Terry Thorley, describes:

*(The panels) just say, “That’s him” or her, and it just becomes like a portrait really. It just becomes a little time capsule of those people and who they were, what they were, what their character was like (Thorley, 1993)*

The Quilt was originally an American project that drew on the long tradition of quilting as a folk art: quilts are traditionally passed through generations, symbolising heritage, family loyalty and connection to place. The American AIDS Quilt deliberately sought to tap into (and perhaps subvert) a sentiment of nostalgia, reminiscent of nineteenth century sewing bees, community and rural tradition (Hawkins, 1993:757). While there is some quilting history in Australia – most notably the use of quilted banners by Australian trade unions – a quilt does not hold the same symbolic position in Australian culture as it did in the US (Hawkes et al., 1994:4). However, despite some initial criticism of the Quilt being an American import and Australians having no particular symbolic attachment to the idea of a ‘quilt’, both the Quilt and Candlelight Memorials became a rallying point for people

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who had been directly affected by HIV/AIDS, most notably the gay community (Carswell, 2005).

**Memorial as Political Strategy**

In his book on the Bubonic Plague, Johannes Nohl writes that one of the major contributory factors to the evolution of social institutions and burial rites during this period was the community’s “loss of confidence in the establishments’ (medical, church and state) powers to control or cure these deadly diseases” (quoted in Lewis and Ross, 1995:124). A loss of faith in formal traditions and institutions led to new practices for both commemorating death and protecting the living. The establishment of AIDS Memorials invites a similar analysis of history. The stigma surrounding HIV/AIDS meant there was no formal recognition for HIV/AIDS as a ‘national tragedy’, nor would there be moves to commemorate formally those who had died from the virus in a manner that often occurs following events such as natural disasters or wars. The Quilt and Candlelight Vigils gave people an opportunity to grieve collectively and publicly.

AIDS Memorials also functioned as a ritual of remembrance, akin in many ways to collective funeral rites. Throughout the 1980s the gay community was enduring the illness and loss of large numbers of its members, yet there was a void of institutional recognition of this. While the individual funerals of many who died from AIDS were undoubtedly held in churches, collectively the gay community was ostracised from the central institutions through which traditional rites associated with death are performed in Australia. Certainly the mainstream churches would have been unlikely
to play a leadership role in any formal memorialising of people killed by AIDS. Gerard Lawrence, the organiser of the 1993 Candlelight Memorial held in Sydney and attended by 5000 people, confirmed this in his statement:

We have to find ways of dealing with our losses ... Many find funerals are too religious and do not work for them. With the AIDS Memorial Quilt, wakes, and with Candlelight, people have found new ways of arranging the needed ceremony, a framework for the process of death that is appropriate for us (Lawrence cited in Editorial, Canberra Times, 1993:3).

Public memorials and monuments influence both the collective memory of a society and public attitudes toward the present. War memorials, for instance, generate an image of soldiers as brave heroes or martyrs. Acts of memorial, such as the Gallipoli ‘dawn service’, serve not only to define Australian history but to influence attitudes toward war in the present day. Modern soldiers are ‘remembered’ alongside those from WWI as heroes deserving of respect and recognition. Gallipoli is signified as a defining moment in Australia’s history (Capozzolo, 2002:94; Hawkins, 1993:762). Memorials, in this sense, are highly political in that they directly contribute to the shaping of history and identity.

The term ‘counter-memorial’ is sometimes used to describe memorials that attempt to challenge mainstream attitudes, or draw attention to an alternative conception of reality (Bold et al., 2002:128). The Quilt Project and Candlelight Memorials can be
seen as counter memorials in that they form part of political protest – a reaction to mainstream institutions. Yet their intention is not dissimilar to state memorials. In the way that the Gallipoli ceremonies construct a particular image, and collective memory, of that battle and the soldiers who fought it, AIDS memorials seek to influence public perceptions of people who have died from AIDS. What makes a project like the AIDS Quilt a ‘counter-memorial’ is that fact that it challenges much of the public imagery around HIV/AIDS and the stigma cast upon people with AIDS. The very act of memorialising an individual, or group of individuals, is in itself a declaration that they deserve to be remembered in a way that is dignified and celebrated. It asserts that people who die from AIDS are morally worthy of a public memorial (Olick and Robbins, 1998:108). In other words, AIDS memorials became a space for articulating and performing the ‘frame’ of the AIDS movement and the attempts of the movement to reduce stigma and discrimination around both AIDS and homosexuality.

*The Quilt could make a profoundly political statement just by the positioning of panels. Having gay men next to children who had died of AIDS made a statement (about AIDS affecting everyone, the egalitarian nature of the Quilt, everyone deserving equal respect) (Carswell, 2005a)*\(^{181}\).

Bold et al. (2002) argue that for counter-memorials to be effective they must be incorporated into a broader activist agenda – something that is used to make broader political claims rather than a functioning as a gesture toward emotional ‘closure’.

\(^{181}\) Phil Carswell interviewed by the author on 17 December 2005.
They illustrate this point with reference to 'Marianne’s Park', a small urban park in Canada which was deemed a memorial to a woman killed by her male partner in an act of violence. Bold et al. discuss the use of Marianne’s Park as a rallying point for feminist action, namely the annual ‘Take Back the Night’ march where women rally in protest of gender-based violence. On its own, Marianne’s Park is a tribute to an individual woman. But when it used as the location for collective protest, the memorial exposes this one act of violence as part of a broader issue of systematic, gender-based aggression and not a random or isolated act. That is, Marianne’s Park could be read as a tribute to one woman, an act of ‘closure’ on the brutality of her life. But it can also be used in the context of movement action to make much broader political claims (Bold et al., 2002:128). In other words, memorials are only politically meaningful to the extent that they are used to continually re-create social memory and social knowledge.

If hegemonic memorialising is often about active forgetting – individualising as well as remembering on behalf of communities – counter-memorialising needs to promote active remembering – enacting the link between remembering the past and changing the future, which involves communities taking responsibility for the systematic nature of gendered violence (Bold et al., 2002:130).

In Australia, AIDS memorials – particularly the Quilt – received widescale public attention, becoming part of HIV/AIDS prevention education as well as being integrated into political protest strategies.
First and foremost [the purpose of the Quilt is] to be there for those people to create the Quilt. But if we just created a Quilt that was static, that would defeat the purpose of being ... I mean, we'd just have a room full of quilts and what's the point of that? It's the ability then to take the Quilt back into the community, to give it back to the community and to utilise it for really positive reasons ... To make people aware. To use it to support safe sex education. That's very important (Thorley, 1993).  

Opportunities were created for broad sectors of the community to view the Quilt: in public libraries, schools, museums and galleries. Candlelight Memorials have attracted up to 8000 people in any one city, and up to 60,000 across the country. Arguably, these two initiatives have reached the broader public to a greater extent than any other actions of the AIDS movement.

Some of the most powerful displays have been when shops have displayed the Quilt panels in their windows. Suddenly people are stopping and reading — reading people's stories, looking at the panels. I have never underestimated the power of the Quilt as a political tool (Carswell, 2005a).  

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183 Phil Carswell interviewed by the author on 17 December 2005.
The Quilt has been the subject of numerous news and feature articles. In 1989, *ITA Magazine* featured a five-page spread including interviews with mothers and children of people who had died of AIDS, as well as with the lovers of gay men (Woodhouse, 1989:106-110). The Quilt also tended to attract interest from the mainstream media, which generally produced articles that were supportive of the Quilt Project. These usually featured anecdotes about the families who produced panels for their children, running headlines such as, “Honour the Courage of Those Living with AIDS” (Frith, 1993:2) and “AIDS Quilt Brings Comfort to Community” (Dennis, 2001:7). The Quilt has been displayed in numerous public locations, including Sydney’s Darling Harbour and the National Gallery in Victoria. Several panels were also displayed at the National Gallery of Australia in 1994 as part of an exhibition, *Don’t Leave Me This Way: Art in the Age of AIDS*. The Quilt has regularly been taken into schools and in some cases school students have made panels, either dedicated to a person they knew or a general panel acknowledging their support for people with AIDS (Woodhouse, 1989:10).

Internationally, AIDS Quilts reached almost iconic statutes for their striking representation of the mortal impact of HIV/AIDS. The American Quilt found its way into popular culture as a feature on the television talk show *Nightline* in 1988. It also appeared in an episode of daytime soap opera *All My Children*. A documentary film, *Common Thread: Stories from the Quilt*, made in 1989, received an Academy Award. The same year, the Quilt was nominated for a Nobel Peace Prize (Stull, 2001:84).
Moreover, by involving the extended families of people who have died from AIDS, the Quilt has been an important outreach tool – a link between the gay community and the broader public. This link is evident in the Quilt panels themselves, many of which have been made by community groups, hospices and gaols. Quilt panels read: *Mount Alvernia (hospital). Keeping the flame of compassion alive... : Maitland Gaol. In memory of all those Inmates who have passed on: Family Planning NSW – Health Promise Promotion Unity Unit: The Continuing Care Unit. Alfred Hospital, Melbourne. 1997: Royal Melbourne Nurses, Care and Remember...*

I got to the [Quilt] workshops every Saturday ... You’re dealing with the mums and the dads and the lovers and the families, and you know you’re providing an avenue for them to release some of their grief and to feel good about themselves and to feel okay about what’s happened. It has a real rounding-off feeling to it, a real closure. I know that every person who goes to a Quilt workshop is a committed person. They will go and they will argue with their friends and their families and their neighbours, and put forward the point of view that everybody should take notice of this disease. They’re the best educators (Carswell cited in Hawkes et al., 1994:60).

AIDS memorials also encouraged people within the gay community to become involved. Candlelight Memorials/Vigils became the largest public rallies seen in Australia around HIV/AIDS. As activist Phil Carswell describes:
People came to Candlelight Vigils who never came to other AIDS events. The bars in Melbourne would advertise them, put together clips to play on their video screens. It was a community event, one of those things everyone assumed you would go to – like a dance party. People would go to [Sydney Gay and Lesbian] Mardi Gras and they'd go to the Vigil (Carswell, 2005a)\(^{184}\).

Although the expression of grief and the opportunity to pay respects to those who had died were the primary focus of Candlelight Memorials and Quilt gatherings, the events were highly politically charged. They became a chance to connect the grief and loss being experienced by individuals with demands for tangible political change. This was articulated well by Justice Michael Kirby who presented a formal address at the unfolding of the Quilt in the Sydney Convention and Exhibition Centre at Darling Harbour in 1999. Kirby said:

I think of the friends that I have lost. I go through their names like a Rosary (and this despite a stern Protestant upbringing). A Rosary of much loved human spirits. Of Peter, a school friend. Of Daniel, the artist in Paris. Of another Peter from England … But remembering and thinking is not enough. Celebrating their lives and recalling their strengths and joys and little foibles, recorded in these cloths, is not enough. These quilts, and the people they remember, propel us to action … On this last note we should dedicate

\(^{184}\) Phil Carswell interviewed by the author on 17 December 2005.
ourselves here and now. We should do so in the presence of these quilts and the spirits that they memorialise. We should demand an end to the last vestiges of prejudice and discrimination that still lurk in the hidden, and not so hidden, corners of Australian society ... Remembrance is not enough. Sorrow, is not enough ... These are days for action, lest receding memories and apathy and political time-serving take over (Kirby, 1999).

The Politics of Empathy

The Quilt illustrates the human side of HIV/AIDS. Rather than didactically informing people about the number of AIDS deaths or the nature of HIV transmission, it is a device for story-telling, introducing viewers of the Quilt to some intimate details of the lives of people with AIDS. It is the details depicted on the Quilt that tend to connect viewers personally to it. Someone who previously had no association with HIV/AIDS can suddenly find a connection between themselves and someone on the Quilt – the same birthdate, similar interests, the same name (Carswell, 2005a; Hawkes et al., 1994:2; Capozzolo, 2002:96; Committee, 1992).

[One of the Quilt volunteers/presenters] used to tell the story that there was this little boy, and [the volunteer had] taken down one of the panels with a pair of jeans on it. And this little boy became fascinated with them and, you know, kept coming back: “Were they his favourite pair of jeans?” “Yes”. And a little bit later came back: “He must’ve loved those jeans.” And just this little cycle of this boy connecting with the jeans ... I mean, if his
knowledge of AIDS comes through connecting with that pair of jeans then, you know, it's a learning thing (Thorley, 1993).  

You could take a Quilt panel to a public event and immediately have people on side. I've done dozens of school talks, and as soon as you tell a story behind a Quilt panel the kids start to make a connection – a connection that all the leaflets and badges can't make. One student saw a panel of a person who had the same birthdate as her and I bet she still thinks about that person on World AIDS Day. We would take videos of the Quilt to public talks – we made up a 10-minute video. The visual nature of these made it very easy to start a talk with. You saw images of these beautiful young people who just shouldn't have died as early as they did (Carswell, 2005a).  

Empathy is created through the connection people make between themselves and someone who has died from AIDS. The symbolic distance between the lives of people with HIV/AIDS and the lives of those viewing the Quilt is lessened. The Quilt in this way plays a role in extending the emotional impact of the AIDS epidemic beyond the borders of the gay community. By humanising and eliciting feelings of empathy with those generally lumped in the category of ‘other’ – stigmatised minorities, gay men, people with AIDS – the Quilt rejects relegation of HIV/AIDS to someone else’s problem. The incitement of empathy in this context has political impact because it introduces the idea that HIV/AIDS affects ordinary people

186 Phil Carswell interviewed by the author on 17 December 2005.
and is therefore a problem for the whole community. Empathy can also go a long way toward recasting prejudice toward both gay men and people with HIV/AIDS.

Marita Sturken describes the Quilt as “bright, colourful, easy to understand, and moving, a perfect human interest story on the evening news or in the local paper” (Sturken, 1997:213). She goes on to discuss how this has created some cynicism among US activists for sanitising the experience of AIDS. The mainstream public accepts the Quilt because it doesn’t make many references to the sexuality or sex lives of gay men. Nor does it carry imagery associated with sickness and death. In this sense, the Quilt doesn’t challenge deep-seated homophobia and AIDS-related stigma. However, even critics of the Quilt acknowledge its capacity to personalise and humanise the plight of people with AIDS (Sturken, 1997:212-213). AIDS Memorials may not directly tackle homophobia and prejudice, but they do introduce an alternative moral framework. It is this that makes memorials a profound form of cultural activism. They are concerned not with formal political engagement, but with the production of social and moral codes. They also tap directly into emotional sentiment as a means of challenging the social reality of people outside the movement (or the community most directly affected).

**The Right to Grieve**

Challenging ‘emotion codes’ has been part of the explicit agenda of many social movements. The Gay Pride Movement, for instance, and the Civil Rights Movement both sought to make visible ‘bad’ feelings associated with stigmatised identities,
such as shame and guilt, and replace them with a sense of pride in one’s identity. The Gay Pride Movement asserted that feelings of self-esteem and happiness should be the acceptable and ‘rational’ way to feel toward gay identity, rather than the sense of shame, distress or sadness that had become the ‘normalised’ reaction to being gay (certainly people had not previously been encouraged to feel proud about discovering they had homosexual desires). These movements both sought to rewrite what Arlie Hoitschild has termed ‘feeling rules’ – the cultural norms which guide individuals in the expression and sensation of emotion (Hochschild, 1998:7; Jasper, 1998:408; Flam, 2005:30; Taylor and Rupp, 2002:142). The aim of a social movement in this context is not just to change the way in which a social group is perceived by society, but to change the experience of belonging to that group – to assert that the experience of being gay is positive and worthy of pride. In this sense, the target of the movement is its own constituents as much as it is the mainstream public. Indeed the very act of developing a sense of solidarity with others may in itself become a positive emotional experience, more conducive to feelings of pleasure and confidence than shame or ambivalence (Taylor, 2000:271-275; Jasper, 1998:418; Caron, 2003; Nugteren 2001).

The social stigma of AIDS complicated the process of grief for many people, especially the families of gay men who lived in mainstream, heterosexual society without connection to others affected by HIV/AIDS. The usual sources of support that may be present following the death of a child, sibling, friend or parent were not necessarily available in the case of AIDS, where community attitudes were often hostile. Even where support was present, the experience of grief could be
overshadowed by a sense of indignity or dishonour that came with a family member’s death from AIDS. In some instances, families would deny publicly that HIV had been the cause of death, blaming another illness such as cancer (Thorley, 1993). For the lovers of gay men, their grief was often not acknowledged by the biological families of those who had died. In many cases, gay men were excluded from their partner’s funeral or other family-controlled burial rites (Holst-Warhaft, 2000:126; Wettergren, 2005:648; Fowlkes, 1990:648)

Grief fits into a social code that Martha Fowlkes describes as a ‘morality of loss’ (1990:637). Social evaluation of the nature and extent of a person’s loss determines the concessions made to an individual’s grief. For example, the loss of a marriage through death or divorce is generally recognised by the community. Sadness is expected and funeral rituals include playing homage to the individual’s bereavement. However, in cases where the relationship does not fit into accepted moral codes, such as with an adulterous affair or in many cases with homosexual relationships, the community does not recognise or acknowledge the grieving partner. Also, where the individual who has died has breached certain social or moral expectations, as would have been the case with many gay men who died from AIDS, there are generally fewer accommodations made for grieving loved ones. Indeed the sense of loss an individual experiences in these cases may be recorded as illegitimate (Fowlkes, 1990:637 and 645). As Fowlkes articulates:

The “spoiled identity” of which stigma is constructed has the power to contravene or cancel out the meaning of loss even where kinship is
concerned. The mourner encounters hostility and disregard, and these add to and underscore the pain of the loss itself (Fowlkes, 1990:648) (emphasis in original).

AIDS memorials were created to provide support to people who had lost loved ones to AIDS. But also, through creating a forum where grief for people with AIDS was legitimised, AIDS memorials sought to change an experience that was, for many people, filled with feelings of embarrassment or shame. Moreover, it deliberately made space for those whose sense of loss may not have been recognised in the funeral of people they had known – namely the friends and lovers of gay men.

However, the nature of AIDS means that these memorials were highly politicised acts. Experienced individually, grief is a personal process, but the collective expression of grief and mourning facilitated by AIDS memorials demonstrates a refusal by large numbers of people to yield to the stigma around AIDS. The political power of collective action in this instance is asserted through the creation of space within which the expression of a particular emotional state is legitimised and respected – a space that didn’t previously exist within the stigma of AIDS. By asserting the right to grieve and acknowledging that grief, AIDS activists challenged the negative cultural and moral status of HIV/AIDS and the people most affected by it.
Breaching the Moral Code

Tova Benski is interested in the possibility for social movement performances to become 'breaching events'. By this she means that movement action can present a moral or ethical stance that contradicts common assumptions or social norms. Social movements pose symbolic resistance to the social order when they expose the social and moral codes that are engrained in cultural processes by presenting a different reading of reality (Benski, 2005:59). She illustrates this with a discussion of the 'Women in Black' vigils, which were a series of peace protests held by a group of women in Israel (calls for Israeli/Palestinian reconciliation). Benski suggests that the significance of a 'breaching event' can be witnessed in the emotional reaction of spectators. Negative reactions from observers tend to follow a significant violation of moral codes. In her study, Benski found that the majority of people who witnessed the vigils expressed anger or contempt toward protestors – shouting at them or making angry gestures. Benski argues that the protestors incited anger amongst spectators because their actions breached dominant and deeply engrained attitudes toward both Israeli/Palestinian politics and the role of women in politics. Women publicly expressing a political position in this context confronted the moral sensibilities of spectators (Benski 2005:74).

AIDS activists were well aware that their actions challenged mainstream moral attitudes towards both gay men and HIV/AIDS. The very act of commemorating people who had died from AIDS was confronting in terms of the stigma surrounding HIV/AIDS. But Quilt Project organisers sought to control as much as possible the reaction of outsiders and spectators by creating a particular 'mood' at Quilt events. A
series of rituals were performed at Quilt unfoldings to solemnise the process of handing over new quilt panels from those who made them to the ‘public project’. Trained volunteers encircled each Quilt panel and unfolded it in choreographed unison. People wore simple, white outfits to ensure their dress did not detract from the detail of panels. The unfolding was accompanied by a public recitation of names from the Quilt, often read by prominent community figures (Project, 2004). The rituals around Quilt unfoldings and viewings, along with the visual impact of a candlelight procession, were designed to be deliberately quiet and calming – setting up a particular emotional experience for both participants and spectators. The rituals were similar to those that govern action in a church or sacred site, and the mood evoked was similar. By creating such an atmosphere, the emotional reaction of participants and spectators tends toward sadness or quiet reflection, leaving limited room for public heckling or derision. As Quilt organiser Phil Carswell describes: “There is something approaching reverence for the Quilt. People are always extremely respectful. Even children always behave at the Quilt, they pick up on the atmosphere” (Carswell, 2005a). Activists worked to counter the possibility of antagonistic reactions to the ‘breaching event’ by controlling the environment – using visual and emotional codes to illicit a particular response.

People participated in the Quilt because the ‘aura’ of the quilt overtook the fear of vilification or other stigma. When all the panels were displayed

187 I use the past tense in this chapter because I am referring specifically to events that took place in the 1980s and 1990s. To my knowledge, however, these rituals are still practiced when new Quilt panels are unveiled.

188 Phil Carswell interviewed by the author on 17 December 2005.
together it was amazing. Like an oasis of amazing tranquility (Carswell, 2005).  

The emotional dynamics of grief and loss are personally and culturally familiar to most people. One doesn’t have to be gay or affected by HIV/AIDS to understand sadness and loss. AIDS memorials tapped into a common moral framework of ‘respect for the dead’ and utilised the familiar cultural cues that have developed around rituals such as funerals and religious services (Collins, 2001:31). In other words, the Quilt and the Candlelight Memorial were respected by outsiders because they used common cultural codes to invoke respect and solemnity.

Conclusion

AIDS memorials were certainly not a confrontational form of political activism. Neither the Quilt Project nor Candlelight Memorials made overt demands on the community or the state. Indeed the nature of such memorials could be seen as ‘asking’ politely for a place in mainstream society rather than pushing for more radical social change. But since their inception, AIDS memorials involved literally thousands of people, many from outside the gay community, in a form of community protest against stigma and discrimination. These memorials have captured the attention of political leaders and the broader community and became a focal point of both the politics of HIV/AIDS and HIV prevention education.

Phil Carswell interviewed by the author on 17 December 2005.
What we were fighting [against] for so long was invisibility. We had sensationalist stories in the media and images of skeletal people dying of AIDS. But most people never knew anyone dying from AIDS. The Quilt gave visibility to the real lives of people. It made that gut level, primal connection that people in the gay community had from knowing people who had died from AIDS. But those in the broader community hadn’t been up close and personal. The Quilt was as up close and personal as you can get without holding them in your arms (Carswell, 2005a) \(^{190}\).

Through paying tribute to people who had died from AIDS, and respectfully acknowledging those grieving for them, the Quilt Project and Candlelight Memorials recast the moral context of HIV/AIDS. They insisted that people who had died from AIDS deserved public memorial even in cases where the virus had been acquired through perceived ‘immoral’ means. As well as supporting individuals in their grief, the public display of respect for both those who had died and those who were grieving challenged the stigma surrounding both HIV/AIDS and homosexuality.

The success of the Quilt itself may indeed be evidence of the fact that public attitudes toward gay men had been changed over the course of the AIDS epidemic. The public was willing to accept, and be involved with, the Quilt and with gay men in a way they may not have been early in the 1980s when fear and uncertainty about HIV/AIDS was at its height. Over time, the fear of being publicly outed as a person

\(^{190}\) Phil Carswell interviewed by the author on 17 December 2005.
with AIDS was also mitigated, indicated through the greater willingness of people to be identified on Quilt panels over time.

*Back in the '80s when the project ... was first started there was still a lot of fear and secrecy and discrimination surrounding AIDS. So a lot of the panels weren’t clearly personally identifying, in that they would come in with initials or just Christian names. Now I think there has been a change in that circumstance. I mean, it’s still not ideal but there has been a change. But the panels are becoming more elaborate, more openly expressive of personality and character* (Thorley, 1993)\(^{191}\).

Social movements are a part of history and are engaged in a social process of ‘knowledge-making’. They seek to influence the cultural and moral scripts that frame everyday life. AIDS memorialising, as a social movement strategy, became a means through which the AIDS movement ‘frame’ was expressed. That is, AIDS memorials both reflected and reinforced the ideological stance of the AIDS movement using imagery and emotion rather than an articulated ideological argument. In this context, the movement frame can be seen as co-currently intellectually and emotionally driven.

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Conclusion

Events disrupt the operative systems of ideas, beliefs, values, roles, and institutional practices of a given society. In so doing, events change the way in which social actors think about the meaning and importance they assign to modes of action and the rules that govern interaction, groups and their discourses, symbols, and rituals. In the event, the meanings carried by cultural objects are embodied in historic consequences (real or perceived) the event has for particular actors (Ellingson, 1995:103).

Largescale or unpredictable events can rupture social convention and change people’s attitudes toward the world. Everyday modes of being – the habits, customs and patterns of thought that frame our everyday existence – are rarely questioned unless something happens to disrupt them or expose their arbitrariness. Bourdieu described as ‘doxa’ the framework of knowledge through which we think. Doxa is not a reference to the conscious ideas that we have or the particular arguments and thoughts that fill our conversation, but the underlying assumptions that inform and structure our ways of thinking. That which is in the realm of doxa is knowledge so taken-for-granted and ubiquitous that it is virtually invisible (Bourdieu, 1977:169; Charlesworth, 2000:31). Public debate usually sits within the framework of ‘what is known’ about the way the world is, even when there is argument or dissent within that framework. According to Bourdieu, social knowledge does not move from the realm of doxa into conscious awareness and discussion as a consequence of the
thoughts or ideas of individuals. Rather, the potential for new or previously unspoken knowledges to enter ‘discursive consciousness’ is created through a change in social conditions. That is, Bourdieu sees a materially based dialectic between social conditions and knowledge. The assumptions that underlie the way we think are only questioned when something forces those assumptions to be made visible (Bourdieu, 1977:166).

This thesis has looked at the impact of HIV/AIDS on Australian society. While for most Australians HIV/AIDS probably sat only in the periphery of their everyday world, for those close to it, the virus produced massive social and emotional upheaval. It was perhaps the most significant event ever to affect communities of gay men, not only because it threatened lives but because ideas about the nature and morality of homosexuality were pushed so starkly into the public spotlight. While this may not have exposed on any grand scale the ‘doxic framework’ into which knowledge about homosexuality is formed, HIV interrupted ‘everyday’ social patterns enough to create opportunities for gay men to influence public knowledge of, and attitudes toward, homosexuality in a way that they never previously been able to.

I think gay people and other marginalised groups in and around them staked a place in the sun and they won’t be tossed ... The question you can ask is: “Well, was it worth having HIV to have that happen?” The answer is no. It’s not ... It’s a bit like WWII, it greatly advantaged the position of women ... But given the choice between oppression of women and World War II, what would you have had? It’s a terrible question to ask. But social
upheaval and these things have a habit of busting up very conservative social structures. So I think you can make that point. You never get a chance to choose between the liberation of women and WWII, you just make the point that it reconfigures things and power and visibility, and HIV and AIDS did that around the world (Bowtell, 2005)\textsuperscript{192}.

The early and effective mobilisation of the gay community around AIDS meant that gay men were in a position to develop a profile in debates about both HIV/AIDS and homosexuality. For the first time, rather than being spoken about by medical or legal 'experts', gay men themselves had a political and public voice and identity. It was this that exposed and undermined previous ways of thinking about homosexuality. A new consciousness about the way gay men (and by association lesbians) live their lives and engage with the community was given space to air. Ideas about homosexuality not associated, as they previously had been, with illness, immorality or criminality became part of mainstream public imagery.

In making these points, in no way do I wish to suggest that the AIDS movement was miraculously able to eradicate homophobia or inequality based on sexuality from Australian culture. Indeed, on the day that I first sat down to write this conclusion (in the latter half of 2006) the Australian press was reporting on a National Day of Action organised by gay and lesbian activists to demand formal state recognition of homosexual relationships. Violence is a lingering threat in the background, and unfortunately occasionally the foreground, of the lives of all gay men and women.

\textsuperscript{192} Bill Bowtell interviewed by the author on 28 May 2005.
Homophobic attitudes underlie much of Australian culture, with 'poofter jokes' and derogatory references to gay men a commonplace part of the Australian vernacular. That being said, the situation for gay men and lesbians in Australia today has changed dramatically from the time when any public discussion about gay people occurred in the context of how to punish or cure the 'affliction' of misdirected sexuality. But the story of the Australian AIDS movement and homosexual liberation is not one that, as yet, has an end. What I have presented here is one part of that story.

Public Influence and Gay Identity

In the early days of HIV/AIDS, gay men tended to be blamed for it. Gay lifestyles were regularly portrayed as the cause of HIV/AIDS and there was a sense that many people saw a terminal illness such as AIDS as a predictable extension of perceived immoral or deviant forms of sexuality. Negative stereotypes of gay men and homosexuality were used in attempts to dissuade the Federal Government from supporting AIDS activists financially and politically, and the so-called 'gay lobby' was characterised as irresponsible, acting selfishly against the health interests of the broader community.

This thesis has demonstrated that, although the AIDS movement mobilised from a defensive position, HIV/AIDS also gave gay men an opportunity to develop a positive public identity that they had not previously had. Rather than being spoken about by medical experts or legal authorities, AIDS activists maintained a regular presence in the media giving gay people an opportunity to project their own image
and their own opinions about homosexuality and gay identity. Many AIDS activists were skilled, educated and articulate people who were highly effective advocates for both the gay community and HIV/AIDS. This image challenged negative stereotypes of gay men as deviant, hedonistic or irresponsible.

The power to determine the way in which the social world is perceived – to make one’s ‘truth’ accepted as universal and natural – is to a large extent what is at stake in political struggle (Lovell, 2004:51; Bourdieu, 1985:729). At issue for all social movements is how to achieve wide-scale acceptance for their ‘cultural frame’ and for their social and political values and ideas. To this end, all social movements engage in ‘identity politics’ of a sort. A high-profile scientist, for instance, is often more likely to gain media airplay for an argument about the dangers of global warming than an environmental activist. Social movements actors will use their ‘expert’ supporters and public intellectuals strategically. But for the AIDS movement, the public presence of gay men themselves, rather than ‘experts’ representing them, was central to achieving the shift in public attitudes toward gay men and lesbians that it did. What had been absent from previous public discussion about homosexuality was any sort of high-profile, regular presence of gay people talking about homosexuality. Through AIDS activism, ‘gay identity’ achieved greater legitimacy and visibility in the public realm. In this sense, as well as influencing the direction of HIV/AIDS policy, a large part of the impact of the AIDS movement could be described as cultural – an influence directed more toward civil society than the state, one that challenged cultural codes and conventions (Melucci and Avritzer 2000: 509). The cultural impact of the AIDS movement was witnessed in such things as the
increasing acknowledgement of gay youth in mainstream health and welfare service and education.

A Politics of Knowledge

The public legitimacy and authority that AIDS activists achieved was also what enabled them to influence the direction of HIV/AIDS policy-making in the public health and medical arena. In any public debate around a ‘health issue’, doctors and medical researchers have a presumed authority that comes from the social standing of medical and scientific knowledge. While not discounting the relevance of scientific and medical training, or the capacity of doctors to heal bodies, it is rare for laypeople be afforded equal weight for their opinions on health matters – even where the health issue or condition affects them personally. AIDS activists challenged this entrenched authority of western medical professionals in two key ways. Firstly, their commitment to a community-led response to HIV/AIDS prevention demonstrated an alternative to the traditional, western model of public health. Through the work of AIDS activists, ideas about public health came to be re-packaged as issues related to complex structures of social justice and community capacity, rather than being seen as purely a clinical or medical concern. Secondly, AIDS activists asserted that the knowledge of lay people had relevance to scientific and medical research – that the experience of living with the disease was a credible form of medical expertise.

On both these points, the AIDS movement introduced an alternative framework of knowledge to the scientific domain. The outcome of this wasn’t an undermining of medical knowledge. Indeed one of the major strategies of AIDS activists was to increase their literacy in medical language so as to communicate on these terms with
doctors and researchers. What the AIDS movement did achieve, however, was to make alternative forms of knowledge relevant to ‘health issues’. It came to be seen as legitimate, for instance, to consult with a wide range of non-medical groups and individuals on public health matters, and for there to be an emphasis on the social elements of disease prevention. Additionally, the AIDS movement opened the boundaries around who could speak credibly on health matters. AIDS activists were able to contribute regularly to media and public discussion about HIV/AIDS. The presence of the AIDS movement in these debates, despite some resistance to this witnessed in forms such as criticism of the gay lobby, came to be considered legitimate and credible. Medical knowledge, in this sense, was no longer the exclusive domain of medical professionals, nor could medical authorities operate with the same level of dominance and autonomy they had previously assumed.

This challenge to medical authority, however, didn’t necessarily come through activists overtly challenging medical professionals – or antagonistic social action. Even though the state and medical authorities were the ‘targets’ of AIDS movement action, the relationship between them was also often collaborative. This is a unique feature of health based movements, which have no choice but to work with their ‘opponents’ given that they are to a large extent dependent on science and medicine for treatment. For social movement research this raises a number of questions about movement building and political impact. For instance, did the inclusion of activists within scientific research institutions lead activists to align themselves with medical knowledge rather than maintaining a critical stance? Did collaboration with medical institutions undermine the radical potential of the movement? Did collaboration with
doctors and scientists lead the movement to become professionalised and exclusive rather than broadly inclusive and open to attracting new activists? While these may be important questions for future research, the point still stands that in the 1980s and early 1990s the AIDS movement did manage to introduce into mainstream consciousness new ways of thinking about public health and scientific research. The fact that there was resistance to AIDS activists' involvement in the public health sector was indicative of the challenge that they presented to dominant cultural codes in this area.

**A New Public Health?**

The terms ‘health consumer’ and ‘consumer health movement’ have become increasingly familiar in the Australian health sector over the past few decades with patient advocacy groups organising across a wide range of illnesses and health-related conditions. However, the Australian AIDS movement represents perhaps the most significant mobilisation around a health issue to date in this country. Indeed, I would argue that the term ‘consumer’ is inappropriate for describing the AIDS movement – a vast underestimation of the leadership role played by activists in this case. There was no sense that AIDS activists were seeking a relationship with the medical profession or the state in which they would simply ‘consume’ services, no matter what level of patient empowerment and consumer choice could be fostered (in fact, when the AIDS movement first mobilised there were no services for HIV/AIDS to be consumed). The AIDS movement has positioned itself as an active participant in all areas of AIDS-related policy and practice in Australia, carving a formal space for community members in decision-making about clinical interventions, government health policy and public health. The impact of this is evident in health
promotion today, where involvement of affected individuals and communities is routinely packaged into public health programs. Even when there is not an identifiable community as there is in Australia with HIV, efforts are made to consult and engage with affected individuals.

In terms of the relationship between social movements and the production of knowledge, this study demonstrates the constitutive role movements play in the production of knowledge. AIDS activists didn’t just resist, or create a block to, medical discourse. Rather, they introduced an alternative way of viewing both HIV/AIDS and public health. The community-based education model of public health demonstrated by the AIDS movement made a significant contribution to ‘normalising’ a socially and politically oriented perspective on public health. In other words, movement actors introduced an alternative non-medicalised paradigm of knowledge into the health system. This demonstrates the way in which social movements create their own lines of discourse and their own knowledges that, in this case, came to intersect with medical knowledge (Eyerman and Jamison, 1991:48 and 55). Social movement also have the potential to recast old ideas into a new context. For instance, as I discussed in chapter one, the environment movement reconfigured scientific knowledge about environmental degradation and pollution into a major political and social issue – one connected to ideas about morality and social justice. The AIDS movement achieved a similar shift in relation to public health, emphasising the social dimensions of disease and illness prevention rather than the medical. Activists highlighted the moral and political framework around which public health is practiced, arguing that some traditional public health measures, such
as compulsory testing or the introduction of punitive containment laws, often
demed necessary in the ‘objective’ interests of public health, could be derived from
homophobic assumptions or mistrust of gay men rather than good science. Their use
of human rights discourse held public health authorities accountable for the social
dimensions of their actions, challenging the notion that the interests of public health
unquestionably held moral precedence over other concerns.

The case of AIDS is also an illustrative example of social shaping of illness. The
way in which HIV/AIDS is perceived today – as a disease linked to social power and
justice, and something which must be dealt with politically and culturally – is a
product of the history of politics around HIV/AIDS, and the struggle between
activists and the medical profession for ‘control’ over the virus. Even a biological
product such as a virus finds its place in the human world through history and
shifting relations of power.

Social Movements: Frameworks of Knowledge and Emotion

Social movements are a part of history. They are engaged in the process of creating
the cultural stories and moral scripts that determine how we perceive the world.
What is interesting about the AIDS movement is that it shows the way in which
movement frames – the type of knowledge they inject into public discourse – aren’t
simply a product of intellectual analysis or rationalised responses to an event. They
are co-currently emotionally, historically and intellectually derived – in this case a
product of fear, grief, historical knowledge and political capacity (Harris, 2006:20).
Social movements emerge in the context of the historical and structural location of their constituents. Gay identity was central to mobilisation of the AIDS movement. Activists mobilised in defense of the rights and freedoms for gay men and lesbians that seemed under threat in the context of AIDS. There was also a lack of confidence in mainstream health services and government to provide necessary support for HIV/AIDS because it was considered to be a gay disease. The ‘frame’ which informed the AIDS movement was a product of the intersection between gay and lesbian history and the fear and grief that swept the gay community in the wake of AIDS.

Social movement ‘frames’ can be described as the ideological position of a movement – the view of social reality adopted by movement activists, and their ideas about what social and political changes are required to improve lives. The history of the Australian AIDS movement suggests the need to look at social movement frames not just in terms of their content and form, but also from the personal and emotional perspective of movement constituents. When HIV/AIDS first emerged members of the gay community were incredibly fearful about what the future held for them. Along with the devastation caused by AIDS itself, people were worried that the virus would inspire a new wave of homophobia and prejudice in society. Obviously, a social group that held a more confident position in the social fabric, and that didn’t have a history of discrimination, would not have experienced the impact of HIV/AIDS in the same way. The AIDS movement mobilised in response to the fears of their constituents and the grief and anger that followed AIDS deaths. The political outlook and strategies adopted by the AIDS movement were based on activists’ knowledge and experience of past injustices as well as their emotional reaction to the
current situation. The AIDS movement began as an intuitive reaction to an uncertain and frightening situation, but this didn’t mean that it didn’t have an intellectual or ‘rational’ basis. Rather, it demonstrates the way in which movement frames are informed at once by emotion, history and political strategy. Movements are not necessarily highly rationalised projects, but nor are they, as early theorists of collective action may have suggested, “the products of unbridled affect, of non rational and irrational wellsprings of action” (Stryker 2000: 2). In other words, the rational/emotional dichotomy, which has long held a presence in social theory, is blurred by close analysis of the production of social movement frames. Knowledge production is shown to be grounded in human reality, not abstract concepts or intellectual debate. In other words, it is people who create new ways of seeing the world, and the creation of new knowledge necessarily occurs through the subjective viewpoint of individuals and their emotional connection to such knowledge. The way in which information is processed, decisions are made and ‘rationalised’ arguments are constructed occurs in a historical context of which emotion is a part.

Much social movement research looks at emotion as stimulating or inspiring movement action – most notably, the emotion of anger and passion. Social movement frames are the conscious attempts by movement leaders to galvanise that emotional energy by creating intellectual arguments that reflect and reinforce the emotional sentiment of movement participants. In the case of the AIDS movement, we see that the movement frame – with its emphasis on human rights and social justice in the face of AIDS – was also used to create space for emotional reaction, such as expressions of grief. This manifestation of emotion in itself became a politicised action (demanding the right for respect in grief) not separable from the
‘intellectual’ frame of the movement. The shifting relationships of trust and mistrust between movement actors and medical professionals was also an emotional stance that worked hand in hand with the strategic goals of the movement. Emotion, in this sense, links the mobilisation of a movement (the emotions that inspire people to act) with the outcome of the movement.

This thesis has demonstrated the interplay of history, discourse and collective action. The history of AIDS is not simply a history of disease, it is a social history through which new ways of viewing the world have emerged. While this study has outlined many of the tangible achievements of the AIDS movement, such as its influence over Government policy or the creation of community based AIDS organisations and effective ‘safe sex’ campaigns, I have also sought to show that social movements can achieve less obvious, but no less significant, social changes. Alberto Melucci refers to the cultural changes effected by social movements as their ‘hidden efficacy’ – shifts in cultural codes or ‘ways of being’ that only become visible over time (1989: 73-75). While such hidden efficacy may be difficult to measure conclusively, a close study of the shifting dynamics of power and relationships, and cultural visibility, that follow a social movement can point to the areas where a movement has challenged conventional cultural, moral or social codes. In the case of the AIDS movement, its major cultural legacies have been to change the way in which gay men and lesbians are perceived and treated by mainstream Australian society. It also challenged some of the long-held cultural patterns of the medical profession, allowing greater scope for non-medical intervention into the domain of health and illness.
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