



HIV and hepatitis C

**policy, discrimination, legal
and ethical issues**



ashm
Australasian Society for HIV Medicine Inc

About ASHM

The Australasian Society for HIV Medicine is the peak representative professional body for medical practitioners and other health care workers in Australasia who work in HIV and related disease areas.

It was formed in 1988 (as the Australian Society of AIDS Physicians). It changed its name in 1989 to reflect a broader membership base and was incorporated in New South Wales in 1990.

The Society is a key partner in the Australian response to HIV, hepatitis and related diseases. It works closely with government, advisory bodies, community agencies and other professional organisations. It conducts a broad Education Program in HIV and viral hepatitis for medical practitioners, health care providers and allied health workers and manages programs of continuing medical education in HIV and viral hepatitis.

ASHM is governed by an elected voluntary board and managed by a small secretariat. It receives support from the Commonwealth Department of Health and Ageing, State and Territory Departments of Health and the pharmaceutical industry. ASHM convenes standing committees on a range of issues affecting its members including education, HIV treatment, viral hepatitis, international/development issues and professional affairs.

Benefits of ASHM membership:

- *Journal Club*, a bi-monthly publication reviewing relevant international journal articles, is mailed to members and is available on the website: www.ashm.org.au
- *ASHMNews*, the members' newsletter, is mailed to members every second month and is also available on the website.
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- By maintaining a comprehensive database of its members' interests, ASHM is able to send its members email alerts on relevant issues and promote various activities to them.



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Foreword

The Hon Justice Michael Kirby AC CMG

This collection of essays describes legal, ethical and discrimination issues presented by two important challenges to global public health: HIV and hepatitis C. The two are distinct yet related conditions. There is an overlap between the individuals and communities exposed to the risk of infection in each case.

The book is, in part, a history; in part, a text on social activism; in part, a description of applicable laws and current problems; and in part, an exploration of how Australians can do better in the future than they have done in the past.

My only warrant to write this Foreword is that I have been watching the epidemics from close quarters, virtually from their start. In particular, when HIV first struck Australasia in the early 1980s, I began to lose close friends to AIDS. I felt compelled to do whatever a non-scientist could to support the response to such an unexpected challenge to human life and happiness. There began an association with the World Health Organization (WHO) Global Commission on AIDS that has grown into more recent activities for UNAIDS (the Joint United Nations Programme on HIV/AIDS) and for the Office of the High Commissioner for Human Rights concerned with human rights aspects of HIV/AIDS. Most of those activities share common features with the response necessary to hepatitis C.

In 1996 I chaired the consultation convened in Geneva that produced the *International Guidelines on HIV/AIDS and Human Rights*. The first draft for those guidelines was prepared by Dr Helen Watchirs, one of the contributors to the present volume. The guidelines drew on international experience and on the strategy of the WHO, in its Global Programme on AIDS, under the inspired leadership of the late Dr Jonathan Mann. From the start, it was realised that HIV/AIDS was not an ordinary challenge to public health. Because of the vulnerable groups that were targeted by the vectors of HIV, special attention had to be given to issues of discrimination. Otherwise, the messages of self-protection propounded by WHO were unlikely to reach the target audiences most at risk.

The guidelines that emerged from the consultation were endorsed by UNAIDS and the High Commissioner for Human Rights in 1998. They insisted on the effectiveness of a 'rights-based' approach to the epidemic, involving the establishment of 'appropriate governmental institutional responsibilities, ... law reform and support services' and the promotion of 'a supporting environment for groups vulnerable to HIV/AIDS and for those living with HIV/AIDS'. Amongst the most vulnerable groups, identified by the consultation were 'women and children, sex workers, injecting drug users and men having sex with men'.

These vulnerable groups have figured high on the agenda of responses to these epidemics in Australia, promoting a similar approach in our national response to the HIV epidemic and, later, to the spread of hepatitis C. John Ballard describes the way policy-making on these subjects emerged in Australia. It is a story not without ups and downs. However, it is one which, on the whole, brings credit upon the capacity of Australian governance to respond quickly, justly and effectively to new and frightening public health developments.

Tim Leach, in his chapter, describes the way the gay community responded and mobilised itself to secure public understanding, medical support and legal reform. In a very real sense, the advent of HIV/AIDS, following so quickly on the decriminalisation of adult male homosexual conduct in Australia, reinforced the awakening of gay consciousness. Out of the shadows of shame and silence emerged a community, freshly mobilised, to insist upon equal rights as citizens and equal respect as human beings.

The third chapter, by Alex Wodak, is written by a courageous proponent of the human rights of injecting drug users. In a world committed to the 'war on drugs' and to sometimes superficial and punitive strategies in that respect, Dr Wodak's consistent, rational, humane and effective voice has promoted an approach of harm minimisation. It is a consequence of his efforts, and those of others like him, that Australia's rates of HIV infection amongst injecting drug users has remained low. How do we keep it that way in a time of message fatigue?

The remaining sections of the book concern issues of discrimination that are inherent in the features of HIV and hepatitis C because of the groups that were targeted, the modes of transmission and the grave health consequences that followed infection.

In the international consultation, to which I have referred, Guideline 5 declared that:

States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasise education and conciliation, and provide for speedy and effective administrative and civil remedies.

The chapters on discrimination must be measured against such international principles. Each of the authors has written in a field with which he or she is familiar. The topics are specialised. They do not cover the whole field of relevant discrimination in Australia, still less the world. But from the vantage point of their expertise, the authors judge our national responses against the criteria that have been stated in universal principles of human rights and in documents such as the international guidelines.

My present work on the UNAIDS Global Panel on HIV/AIDS and Human Rights has taught me that we are approaching, if we are not already at, a critical turning point in that HIV/AIDS epidemic. Until now, bereft of effective therapies, the effort of the global community (and of nations such as Australia) has been substantially focused upon prevention of the further spread of the epidemic. In this regard, we have sought to practise the principles that Jonathan Mann taught. Essential amongst these was the principle that, paradoxically, the best way to prevent further infections and to slow the spread of the virus is by protecting the rights of those specially vulnerable to infection and promoting educational messages addressed to them.

Now we have antiretroviral therapies that promise a reduction in mortality and radical improvement in the health and happiness of persons already exposed to HIV. Difficulties of reducing the cost of these therapies and providing cheap means of screening the huge populations that might benefit from their use have been tackled, and may be overcome.

Yet, on a global and national basis, the chief impediment to effective therapeutic responses remains the problem of discrimination. How do we ensure that millions of people who *might* benefit from the therapies come forward to undergo tests to identify those who might have been exposed to HIV? How do we ensure that those who do are given basic knowledge of the consequences, so that their decision is an informed one, conforming to international human rights standards? How do we provide for ongoing supply of drugs and the accurate monitoring of therapy? How do we ensure against stigma and discrimination that add to the burdens of those who are infected? How, indeed, do we overcome the barrier that fears of such stigma and discrimination present to undergoing the tests that lead to therapy in the first place? How, in developed countries, do we address persisting problems of discrimination and denigration? How do we tackle the sudden rise in HIV seroconversions and the erroneous assumption of some that 'AIDS is over'?

This book does not provide the answers to all of these questions as they affect us in Australia, still less in the wider world of HIV and hepatitis C. Yet the book is a good illustration of the desirable international norm that enjoins us all to think globally and act locally. From our vantage point in Australia, we cannot solve all of the world's problems; but we must contribute to doing so.

We cannot even solve all of our own problems; but it would be irresponsible not to try. One day, we hope, an AIDS vaccine will consign HIV to a footnote to epidemiological history. Twenty years ago the scientists assured the first meeting of the Global Commission on AIDS that such a vaccine would be forthcoming within five years or a decade. Yet so far it has eluded us. Bridget Haire's chapter recounts the saga of AIDS vaccine development. It is a chapter that still has no happy ending.

The issues of HIV and hepatitis C are therefore complex, controversial and difficult. Yet we have made progress. The world seems to have accepted that the old draconian approach of epidemic control will not work in these cases. The countries that have been most successful in responding to HIV and hepatitis C have accepted the paradox. They have promoted human rights principles. They have joined them to public health strategies, effectively for the first time. But the target keeps changing. We must learn to do many things at once.

In Australia, we must continue the efforts addressed at prevention. But we must also respond to the new challenges and opportunities of therapy. We must address our problems at home, including new ones such as with hepatitis C and the recent rise in seroconversions to HIV. Yet we must look beyond our own shores and assist multilateral and bilateral programmes in countries with problems even greater than those of Australia.

Any serious reflection on HIV and hepatitis C will make us aware of the enormity of the challenges. In all truth, these are challenges to humanity greater by far than terrorism and weapons of mass destruction. If only we could mobilise the world to this realisation. This book will not succeed in doing so. Nevertheless, it is an illustration of the old rabbinical principle that Jonathan Mann observed in his life. We cannot, by our puny human efforts, solve all of the world's problems. Yet we are not released from our moral obligation to try.

Justice Kirby is a one-time member of the WHO Global Commission on AIDS. He serves as a member of the UNAIDS Global Panel on HIV/AIDS and Human Rights.

Preface

This monograph was developed in part to recount how Australia has confronted the HIV and hepatitis C epidemics. It is not a history of ASHM's response, nor is it a definitive account of how Australia has or should have responded. Rather it is a collection of writings which focus on key aspects, the challenges that were encountered and the steps forward. It is not a text on how to respond to public health crises, nor is it a recipe for policy development. It simply sets out the benefits and pitfalls as viewed by a number of practitioners in the Australian responses to HIV and hepatitis C.

For those entering a policy, public health or advocacy role, we hope the monograph will provide some enlightening insights. For practitioners and consumers who have been involved in Australia's unique response to HIV and hepatitis C, or those who would like to get involved, we hope it will make an interesting read. There are many stories to be told, these are just some. This collection of writings comes from a range of people, and their perspectives do not reflect the policy or position of the Australasian Society for HIV Medicine. The aim of this monograph is to make people think, to encourage debate, to enrich our response to HIV and viral hepatitis and to provide other areas of health with an insight into some of what has been done in this sector. You may adapt it, adopt it, debate it or discard it.

This monograph presents perspectives on the changes – policy, political, legal, social and ethical – resulting from the emergence of HCV and HIV in this country. Often, in rooms across Australia when personnel gather to train in HIV or HCV medicine and the presentation on 'history' is delivered, comments are made about how HIV and HCV have changed the health system. These chapters illustrate that it is not only the health system that has changed, but all components of the society in which we live.

This collection of perspectives sketches stories of courage and determination, highlights brave and advanced policy decision-making, traces the effects of decisions over time and outlines the trends today. It explores some of the major changes resulting from the emergence of HIV and HCV – partnership, community involvement, community advocacy, drug access, harm minimisation, research methodologies, surveillance systems – and discusses some of the philosophical shifts that have accompanied these changes.

The authors draw their own conclusions, but the ever-present theme is that there is a lot still to do. Learn from the stories and lessons contained in these chapters. Treat them as a means to generate discussion and use these perspectives to inform your own involvement.

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Australian policy-making on HIV and hepatitis C

by John Ballard

If HIV and hepatitis C (HCV) were simply ‘objective’ phenomena – viruses with similar routes of transmission and a lengthy period between transmission and the symptomatic appearance of disease – then the policy response in terms of resource investment might rationally be measured by the relative costs of AIDS and liver failure.

Both HIV and HCV were initially identified through their end-products in specific groups of people, most of whom were stigmatised for the behaviour through which the viruses are transmitted. Although their consequences for morbidity and mortality are quite different, this was not known in the early stages of identification. Both can be transmitted through blood. The collection and refining of blood for medical use through the Red Cross have been financed, if not controlled, by governments in Australia, ensuring that they would be seen as politically responsible for preventing transmission.

In fact, however, HIV and HCV are social artefacts, products of different moments in history. They carry very different social meanings that have broad implications for politics and policy. These can be distinguished in terms of the ways in which HIV and HCV were perceived publicly and politically, the scope for innovation available at the time each virus emerged on the public policy agenda and the capacity of affected communities to contribute substantially to a response.

AIDS first appeared in the media as a deadly disease spread primarily among homosexual men who were perceived as having infected the blood supply. The shape and extent of the threat to ‘the general public’ was unknown. Announcements of the first identification of an AIDS ‘case’ in Australia, then of HIV transmission through the blood supply and the death of three Queensland infants with HIV from blood transfusion, each raised media panic. The response on the part of gay communities in Australian cities from mid-1983 was to develop education and care programs, which effectively changed behaviour before governments became active. The response on the part of the federal government to the Queensland babies panic in November 1984 was exceptionally proactive, putting Australia well in advance of other countries.

The availability of a diagnostic test for HIV was not only the instrument for alerting the government and public to the risk of blood contamination, but was also a constructive focus for early government activity, which made testing publicly accessible by April 1985.

Beyond testing, however, the absence of a medical response to AIDS meant that there was scope for innovation through the concept of health promotion, which had recently given community participation a measure of legitimacy within the public health repertoire. Infectious diseases had been assumed to be obsolescent and specialist institutions were in decline, easing the ascendancy of new approaches to public health and helping to block ownership of AIDS by medical specialists.

As a result there was unusual scope for innovation and collaboration between governments and communities in education, counselling, social research and policy-making. The partnership between officials, the gay community and an AIDS medical community which formed across specialisations became an internationally heralded feature of the Australian response.

If AIDS had not been primarily identified with gay men, the capacity for a community response would have been greatly restricted. Gay communities in Australia, which had been established for no more than a decade, were exceptional for their geographical concentration, their political mobilisation around issues of legality and discrimination, and the range of resources that they could deploy. No other group had comparable community identity, networks, education and media with which to shape the response to an epidemic.

The development of hepatitis C as an issue for public policy had a different trajectory. Not only was its identification a slower process, but its potential impact on public health was only gradually perceived, with the media generating only limited public anxiety. There was much less prestige attached to medical research on hepatitis than on HIV and the terminal effects of the disease failed to produce images generating public concern and sympathy.

Those most affected by hepatitis C were intravenous (IV) drug users, who were much more heavily stigmatised and who lacked a comparable history of mobilisation for policy advocacy. Instead, drug and clinical services (by establishing needle exchange programs), and user groups established under HIV/AIDS auspices (by organising peer education and care), provided the essential basis for a response to hepatitis C. But hepatitis C emerged at a time when HIV/AIDS already occupied the terrain of infectious disease policy and funding in Australia, and the cost of responding to hepatitis C at a comparable level has never been seriously confronted.

What follows is a historical analysis of the groups and issues that shaped HIV and HCV policy in Australia during their formative years. HCV policy followed in the wake of the response to HIV, and the HIV story is inevitably a more extended one with a much wider and more devastating impact.

HIV policy-making

During 1981 and 1982, as AIDS was gradually identified in the US and France, a few Australian medical specialists and gay activists followed American news on

AIDS. Given the links between Australian and US gay communities, it was assumed that AIDS would eventually appear in Australia.

The first Australian case was announced in May 1983. It coincided with a request from the Red Cross Blood Transfusion Service in Sydney that homosexual men not contribute blood and led to the first of several media bouts of panic about AIDS. This in turn led to the establishment of AIDS councils by gay communities, as well as to the appointment of a medical working party by the National Health and Medical Research Council (NHMRC) to prepare guidelines for infection control, patient care and the collection of epidemiological data.

During the year of sporadic activity that followed, the US announced isolation of the virus in April 1984. This made possible the rapid development of a first generation of HIV antibody tests. Because of a tradition of close relationships with US research centres, Australian scientists were among the first to obtain access to US tests, and testing provided awareness in July 1984 of a case of HIV transmission by blood transfusion. By October it was recognised that 30% of those using Factor VIII to treat haemophilia were HIV-positive.

Because of its geographical isolation Australia had, exceptionally, for many years been self-sufficient in blood and blood products. Unlike other governments, the Commonwealth was involved in the funding of blood collection through the Red Cross, as well as the manufacture of Factor VIII through the Commonwealth Serum Laboratories. Government responsibility for the safety of the blood supply meant that AIDS was inevitably a major government concern. While other western governments denied official responsibility, the Commonwealth had no choice.

In November 1984, in the midst of a federal parliamentary election campaign, the Queensland government announced that three infants had died after receiving HIV-contaminated blood collected from a gay donor. To prevent AIDS from becoming a political issue, and to stifle rising hysteria in media coverage, Neal Blewett, as Minister of Health, called an emergency meeting with state health ministers to agree upon a set of initiatives.

Blood donor-exclusion procedures were standardised; the Commonwealth government funded the development of viral test kits, and arranged for Australian scientists to participate in the US evaluation of the kits; and, while a medical AIDS Task Force under Professor David Penington was renewed, a National Advisory Committee on AIDS was also established, with Ita Buttrose as chair. NACAIDS was given responsibility for devising education programs, and included not only medical and legal experts, but also representatives of labour unions and health consumer groups, the Haemophilia Foundation and the Sydney and Melbourne AIDS councils. This set the stage for a continuing turf war and rival advice to Blewett from Penington and NACAIDS.

In this initial response to AIDS as a public issue, Bill Bowtell, as senior adviser in Blewett's office, played a crucial political role. When AIDS suddenly became of

critical importance, the minister's office was able to mobilise political resources and authority to respond with innovative measures. Blewett as minister was fully supportive at a time when most ministers, including the Prime Minister, preferred to avoid the issue. This made it possible for Bowtell and his eventual successor, Michael Clarke, to guide major government initiatives on AIDS in a manner exceptional in health policy development, which was normally left to departmental officials.

Well in advance of government initiatives, however, gay groups and a small band of gay doctors were active. Community forums, and Adam Carr's monthly column in the gay press interpreting current medical thinking, meant that gay communities were well-informed and AIDS councils were prepared to launch safe-sex campaigns. Retrospective epidemiological evidence indicates that the incidence of HIV transmission – over 80% of it through male-to-male sex – peaked in 1984 and began to fall before any government funding of AIDS education programs had begun.

Setting HIV/AIDS policy directions

In the months after November 1984, there was extraordinary government activity concerning AIDS. Blewett and senior officials visited the US for discussions in Washington and at the Centers for Disease Control, and to view medical and community programs in San Francisco and New York. They returned determined not to allow the epidemic to have a similar run in Australia. Substantial resources were mobilised to have all Factor VIII heat-treated by January and the blood supply fully tested by the end of April 1985, several months ahead of most western countries.

In the Commonwealth Department of Health, which was restructured in late 1984 to emphasise health promotion, an AIDS Coordinating Unit was established within the new Division of Health Advancement. The states responded in different ways. In NSW, AIDS remained one of many concerns in the office of the Director of Public Health, while in the ministries of health of Queensland, Tasmania and South Australia AIDS was allocated to offices concerned with sexually transmitted diseases and was dealt with through the traditional containment strategies applied to STDs. By contrast, in Western Australia and Victoria AIDS was allocated to health promotion branches, with quite different results in the early years.

In Victoria, Lynda Stephens, the director of health promotion, considered that only gay men would understand the health education needs of gay men. Against opposition from medical specialists she hired Phil Carswell and Ian Goller of the Victorian AIDS Council to organise community education programs and arranged funding for a Gay Men's Community Health Centre. She provided the Commonwealth AIDS Unit with a model for funding AIDS councils for education and care programs, a model recognising expertise within the councils and

accepting the concept of health promotion through community-based education. While community participation in health programs had become widely practised in Australia over the previous decade, it was codified in the World Health Organization's (WHO) Ottawa Charter only in 1986 and remained an alien concept in many countries.

The rival approaches of medical containment and community education were embodied during 1985–87 in the two advisory committees. Penington claimed authority concerning AIDS issues and argued forcefully for testing 'risk groups', the only available medical response. NACAIDS preferred community-based education concerning safe sex in the absence of any available treatment for those found to be HIV-positive. Blewett's office supported the NACAIDS position and succeeded in insulating the issue from partisan politics by educating a Parliamentary Liaison Group on AIDS. Nonetheless, the government's commitment to a health promotion strategy on AIDS had to be reasserted frequently in the face of continued insistence on mandatory testing and medical control of AIDS policy by Penington and later Bruce Shepherd of the Australian Medical Association.

Community education programs grew rapidly. Early in 1985, the Victorian AIDS Council organised a campaign on safe sex for gay men, emphasising the use of condoms and setting a national model. In Sydney, with a much heavier AIDS caseload and imaginative care programs, the AIDS Council of NSW sought out and collaborated with social researchers at Macquarie University in symbiotic research and education programs which set an international model for innovation.

During the first national conference late in 1985 the AIDS councils, encouraged by the AIDS Coordinating Unit, established the Australian Federation of AIDS Organisations (AFAO). Supported by Commonwealth government funds, it quickly achieved a reputation for pragmatic policy contributions through its executive officer, Warren Talbot, and successive presidents.

The perceived success of community education among gay men led governments to support programs for other groups seen as being at risk. Some GPs and venereologists had already played a significant role in educating gay men, sex workers and IV drug users. Following informal practice, in NSW and Canberra drug services made needle exchanges available from 1986, and the Australian Prostitutes Collective in Sydney was funded for condom education and distribution. Neither of these arrangements raised major public controversy and they were adopted in other states. These early interventions were later credited for the maintenance of low rates of HIV infection in Australia compared with other industrialised societies. They also contributed to the articulation of a strategy of harm reduction, coherent with the principles of health promotion.

At the Paris international AIDS conference of July 1986, it was finally agreed by medical experts that HIV was transmissible by vaginal intercourse, and western

governments responded by beginning to fund public education on AIDS. In Australia, a NACAIDS sub-committee was given responsibility for negotiating a major campaign focused on the 'Grim Reaper' television broadcast of April 1987. Although controversial, this served to place AIDS and condom use on the wider public agenda and helped to mobilise schools and churches for education programs. It also pushed Commonwealth politicians and officials into committing much more substantial funding to AIDS programs.

National and community AIDS education helped to create a greater public willingness to address sexual health, sexuality, sex work and drug use in an open and pragmatic manner. Issues that had not been considered appropriate for public presentation, such as condom use and needle exchange, became matters for rational discussion.

Consolidating policies in a national strategy

Australian policies on AIDS began to receive recognition among other countries for their innovative character. In July 1987, the first regional workshop on AIDS for Asian and Pacific island officials was organised in Sydney by the Commonwealth government and WHO's new Global Programme on AIDS, raising the Australian response to AIDS as an appropriate model. It was followed by study tours of community groups and officials from the region, especially after the first Asia-Pacific AIDS conference, held in Canberra in 1990.

For two years after the Commonwealth election of July 1987, national policy-making on AIDS was focused on the process of developing a strategy that would provide long-term commitment of funding and lock the states of Queensland and Tasmania into nationally defined priorities. Much of this process was designed and steered by Michael Clarke as Blewett's adviser on AIDS.

The rivalry between NACAIDS and Penington's Task Force was superseded by the appointment of an Australian National Council on AIDS (ANCA) with broad representation. During 1988, while a discussion paper was being prepared as background to a national strategy, the Third National Conference on HIV/AIDS was held in Hobart. Whereas conferences in 1985 and 1986 had served to consolidate a national community of interest in AIDS, the 1988 conference was designed by Clarke to canvas a range of outstanding issues.

At the conference, Wilson Tuckey, shadow minister for health, attempted to disrupt the established consensus by blaming those infected through sexual activity and arguing for greater medical control, but he was quickly replaced and a bipartisan approach resumed. The conference provided the occasion for encouraging the mobilisation of communities at risk that had remained unorganised: commercial sex workers, injecting drug users and people living with HIV and AIDS. Clarke took the initiative in facilitating national federations of community organisations for each of these and arranging their affiliation with, and limited funding through, AFAO.

The first step towards a national strategy on HIV/AIDS was the preparation of a discussion paper, *AIDS: A Time to Care – A Time to Act*. Drafted by a team of consultants under Elizabeth Reid, this document laid out the options available concerning each policy area and proposed a set of ethical guiding principles. After the paper was discussed by parliamentary committees and community groups in all states, six panels on key issues held public hearings throughout the country and prepared reports. The exercise served a broad educational function and opened up the range of issues for consideration by drawing on the lessons of practical experience from all communities.

The *First National Strategy on HIV/AIDS* was then drafted by a group within the Commonwealth Department, working to a steering committee composed of officials and, after difficult negotiation, Warren Talbot from AFAO. As with the discussion paper, draft sections of the strategy were discussed at an early stage with an expanded version of the Australian National Council on AIDS, a National AIDS Forum of 33 people drawn from all areas of interest.

Pressure from some doctors for mandatory HIV testing of surgical patients and aggressive contact tracing was rejected. Presented to parliament in August 1989, the strategy was welcomed by the opposition. It confirmed the existing thrust of AIDS policy, requiring informed consent and confidentiality for testing and advocating extension of needle exchange and condom distribution. It also repeated the discussion paper's guiding principles, which have been adopted in many other countries. The Commonwealth committed itself to four years of funding, rising from \$31 million to almost \$68 million per year.

Shortly after adoption of the national strategy, Blewett left the health portfolio after a record seven years, Clarke became Secretary to the new Labor Premier of Tasmania and Elizabeth Reid went off to establish the United Nations Development Program's HIV and Development Programme. Under Blewett's successor, Brian Howe, ministerial involvement in HIV policy was maintained, particularly on new issues of drug approval and clinical trials and the second national strategy. But succeeding Ministers of Health had other priorities, and AIDS policy-making within the national strategy reverted to public servants. Meanwhile AFAO and the state AIDS councils, with substantially increased funding, became more professional and bureaucratic, in many instances generating and preparing policy documents which were simply adopted and re-badged by governments.

Maintaining partnership and commitment

During the 1990s, collaboration among government officials, health professionals and AIDS community-based organisations became known as the 'HIV/AIDS partnership'. Consultative arrangements during the two years of preparation for the national strategy involved all three groups on a basis of equality of expertise and

a wide measure of mutual respect. But it was not always easy to maintain a sense of common enterprise in the face of changing government priorities and competition for funds.

Although the national strategy of 1989 confirmed the directions taken in previous years, several new initiatives stemmed from the strategy. The Intergovernmental Committee on AIDS began collaborative planning among the states on the difficult issues of prison and school programs, and education among youth and indigenous communities. The most ambitious of these was a comprehensive review of law reform required for conformity with the principles and detail of the national strategy. Although implementation of the proposed reforms has been only partial, the review provided a set of documents drawn upon by other countries.

One issue not covered in the first national strategy, which arose shortly after its adoption, was access to new AIDS treatments. Australia maintained a regime of strict import controls on pharmaceuticals, particularly after the thalidomide episode. Although the Commonwealth was quick to make AZT available, other new treatments available in the US required lengthy approval procedures. ACT-UP, a small group of people living with HIV/AIDS modelled on radical groups in the US confronting government inactivity, staged protests over several months in 1990. AFAO successfully lobbied Brian Howe to order a review of drug regulatory and clinical trial approval processes, and the review led to significant reforms ensuring prompt access to new treatment for those with life-threatening illness.

Although diverse and imaginative community education programs were well funded, a greater amount of funding was for many years spent on national education programs commissioned by the Commonwealth department and broadcast through public media, despite evidence that community education programs were more effective.

The growth of AIDS funding produced large organisations in the AIDS bureaux of Departments of Health and in AFAO and some AIDS councils, which, in addition to advocacy and education, delivered care and support services. Increasing professionalism provoked conflict in some councils between employed staff and volunteers. Partnership meant close collaboration between government officials, health professionals and the councils, and the latter became more like extensions of government and less like the community-based associations of the early years.

Partnership was probably at its most collaborative under Brian Howe, when the federal department's HIV/AIDS and Communicable Diseases Branch reached its full extent. AFAO, under Bill Whittaker in the ANCA executive, participated fully in devising the second national strategy and compromises were hammered out. However, under pressure from other health areas to reduce the priority in funding and staff resources given to AIDS, 'mainstreaming' of AIDS programs by absorbing them into broader programs was proposed, though not until 1996 was this seriously undertaken.

In 1996, a major restructuring of the Commonwealth department coincided with the first change of government since 1983 and with the drafting of a third national strategy. The third strategy was preceded in 1995 by the first major evaluation of Australia's AIDS response, which recommended continuing priority for education and prevention programs for homosexually active men, as well as greater attention to programs for indigenous people. The third strategy, unlike its predecessors, was drafted within the department with limited consultation and a restructuring of the department meant that the work of the AIDS branch was diffused within a National Centre for Disease Control that focused on a much wider range of public health issues.

Under the third strategy (1996/1997 to 1998/1999) the policy frameworks, funding arrangements, infrastructure and service delivery structures for HIV/AIDS, hepatitis C and other related diseases were integrated. The main advisory committees on HIV/AIDS were reconstituted as the Australian National Council on AIDS and Related Diseases, with former Senator Chris Puplick as chair, and a parallel official Intergovernmental Committee. Each committee established separate subcommittees on HIV and HCV, which became the main specialist bodies on policy and the focus of further policy-making.

The period of the third strategy coincided with technical advances in treatment. The availability of highly active antiretroviral therapy (HAART) changed power relations and priorities, with increased participation of people living with HIV/AIDS (PLWHA) and diversification of programs among different groups of PLWHA. There were also new forms of participation by doctors and the pharmaceutical companies in what was increasingly perceived as a manageable illness, and a consequent normalisation of public discourse concerning AIDS.

From 1996, under a Coalition federal government there was a managerial reorientation of government. From July 1997, Public Health Partnerships between the Commonwealth and the states came into effect, providing funds to the states without specifying the amounts to be spent on specific program areas such as HIV/AIDS. At the same time, all community-based organisations were placed under much stricter requirements of accountability.

The fourth national strategy on HIV/AIDS (1999/2000 to 2003/2004) was designed to fit with new national strategies on hepatitis C and sexual health, while a long-delayed commitment to a fifth national strategy was announced only at the end of 2003. At this point the whole tradition of partnership was placed in jeopardy by the exclusion of community representatives from a renewed Ministerial Advisory Committee.

HCV policy-making

Hepatitis C emerged as a public health issue in societies which had been coping with the challenge of HIV/AIDS for over a decade. It was inevitable that policies on

HCV would lie in the shadow of well-articulated strategies developed in response to HIV, and this proved both advantageous and problematic for the development and resourcing of the response to HCV.

Identification of hepatitis C was a much more extended process than the tracking down of HIV, reflecting a much lower level of scientific resources allocated to it. While hepatitis A and hepatitis B were distinguished in the 1940s, it was not until after the isolation of HBV antigen in 1965 that it became apparent that a further unidentified virus was producing post-transfusion hepatitis. This was labelled non-A non-B hepatitis from 1975, when its transmission and natural history began to be traced.

Although its prevalence in Australia was found to be low in 1980, it accounted for 78% of post-transfusion hepatitis. Prior to the determination that HIV was blood-borne, it was considered the greatest safety risk in blood transfusion. Surrogate tests for the unidentified virus were available, but were not seen in Australia as sufficiently specific to outweigh the costs of excluding even a small percentage of a chronically short blood supply.

HCV was isolated in 1988 and was found to account for 85% of non-A non-B hepatitis cases. Diagnostic test kits were available within the next year, but their results were largely indeterminate. The choice whether or not to deploy these tests and the earlier surrogate tests preoccupied the blood transfusion services, which at the same time became subject to a new and stringent regulatory regime.

Prior to changes in the Therapeutic Goods Administration Act in 1989, the blood services were self-regulated, but blood safety had become a matter of public concern. Litigation over blood-based HIV transmission also changed the context within which blood had been seen as a gift, and helped produce an increasingly managerial approach to what was now a commodity. At the end of 1989, the risks of litigation for HCV transmission ensured that the new tests, despite their indeterminacy, were adopted at a meeting of the National Blood Transfusion Committee and government representatives. Within a very short period the tests were in place, Australia becoming the second country, after Japan, to screen its blood supply for HCV.

There ensued several years of policy inaction on hepatitis C. While AIDS was initially perceived as a mysterious new threat, hepatitis C was merely one of a set of chronic diseases with which society had lived for decades. Initially it was assumed that blood screening and needle-exchange programs, already in place, were sufficient to check further transmission and that research, education and care programs comparable to those established for HIV were unnecessary.

Governments and AIDS non-government organisations, freshly re-funded under the first national strategy on HIV/AIDS, wanted no diversions or rival programs. There was no mobilised group analogous to the gay community initially identified with hepatitis C and it fell to the only health care group concerned, the

gastroenterologists, to publish in 1991 through the new Australian Gastroenterological Institute the first information on hepatitis C for health providers, patients and the public.

The injecting drug-user groups organised in response to HIV, linked nationally as the Australian Intravenous League (AIVL, now known as the Australian Injecting and Illicit Drug Users' League), began to educate users on the risk of HCV infection, which was much more easily transmissible than HIV. The first hepatitis C councils were formed in 1992/1993 as clinic-based groups providing support, referral and information, similar to the first haemophilia councils, but quite different from the origins of the community-based AIDS councils.

There was no significant HCV epidemiological research underway to verify a widespread assumption that HCV prevalence was static. However, a Melbourne cohort of IV drug users provided Nick Crofts with evidence of a substantial number of new HCV infections. The number of notified cases showed that there was a significant epidemic in Australia: 4116 in 1991, 8812 in 1992, 7573 in 1993 and 8941 in 1994. But a 1993 report in the *Medical Journal of Australia* on HCV incidence, projecting a total of between 80,000 and 100,000 infected, drew no media or government interest.

What impelled the Commonwealth government to take its first action was a campaign by pharmaceutical companies, supported by gastroenterologists and the nascent hepatitis C councils, for subsidised access to interferon, a drug that had been seeking a market for several years. Its high cost led the Commonwealth in 1993 to establish a joint task force of the NHMRC and Australian Health Ministers' Advisory Council (AHMAC) on hepatitis C to work out criteria of eligibility for access to interferon.

Once established, the task force took on a broader role and its report provided the first Australian summary of knowledge concerning HCV. It recommended establishment of a National Reference Laboratory, control and education programs and prevention and treatment protocols.

In June 1994, before the report had been considered, *The Age* and the ABC's *7.30 Report* drew public awareness to hepatitis C, focusing on two infants who had been infected by blood transfusions. They had been identified through a Victorian Red Cross look-back program to identify those who had received HCV-infected blood. An ensuing media frenzy concerning hepatitis C, comparable to that concerning the Queensland HIV-infected babies in 1984, together with demands for compensation, led the Commonwealth Minister to convoke a special AHMAC meeting in August.

In September, interferon was approved for pharmaceutical benefits for a narrow range of persons with hepatitis C, and in October AHMAC endorsed a Victorian proposal for a national action plan for hepatitis C. This was based on the task force report and included community education, epidemiological research

and a national look-back program. To support the national action plan the Commonwealth government allocated A\$3.8 million over two years beginning in 1995/1996 for national surveillance and education.

In March 1996, the arrival in office of a Coalition government coincided with the development of serious attention to hepatitis C. The new government was much less committed to consultation with non-government organisations and was sceptical concerning policies of harm reduction in relation to illegal drugs. Nonetheless, the new Minister for Health and Aged Care, Dr Michael Wooldridge, took an active interest in both HIV/AIDS and hepatitis C and managed to maintain most of the previous government's policies.

The state and territory hepatitis C councils had lobbied for the funding of a national peak body, but were initially given funding only for a national needs-assessment under the direction of a councils reference group. Activists involved in sex worker and drug-user programs in relation to HIV/AIDS had always felt a measure of exclusion and disinterest on the part of gay-dominated AIDS organisations; very limited funding for the AIVL and Scarlet Alliance was provided by the Commonwealth government through the well-resourced AFAO.

The needs-assessment report in August 1996 provided evidence of the need for a national organisation and, with Wooldridge's support, the Australian Hepatitis Council (AHC) was incorporated and funded by the Commonwealth in 1997. Its constituency overlapped with that of AIVL, which had already developed HCV peer-education programs. While AIVL represented the at-risk population with an agenda including the defence and improvement of needle syringe programs, the health of drug users and drug law and policy reform, the Australian Hepatitis Council aimed to represent people in Australia with hepatitis C. The AHC sought to increase public awareness of the condition, expand access to treatment and help reduce the impact of the epidemic by providing education resources and representation. It advocated enhanced hepatitis prevention through harm reduction, and improvement to quality of life through addressing discrimination and stigma against those affected. AIVL, the AHC and AFAO developed a cooperative working relationship.

The new focus on HCV in Wooldridge's department led to a proliferation of consultation and reports. The First Australasian Conference on Hepatitis C was held in March 1997. In February 1998, a substantial increase in research funding, with emphasis on social and epidemiological research, was announced. Then, in preparation for a national strategy on hepatitis C, a major review was undertaken on the model of the first strategy on HIV/AIDS ten years earlier.

The review, involving wide consultation, was conducted by two former officials with broad experience of the response to HIV/AIDS and was published in January 1999. The government accepted its recommendations and set up a complex arrangement for the development of a national strategy: commissioning several

issue papers, circulating a consultation document, organising hearings throughout the country, and holding a national forum to consider a draft national strategy. The peak ministerial advisory body, ANCARD, which auspiced the development of the strategy, was renamed the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD), and so raising the profile of hepatitis C.

The *National Hepatitis C Strategy 1999-2000 to 2003-2004*, launched in June 2000, was the first in the world and joined the 20 national health strategies co-ordinated by the National Public Health Partnership. It specified four priorities: reducing transmission, improving treatments, providing health care and support for those infected, and preventing discrimination and stigma. Funding of \$12.4 million was allocated for its four years of the strategy. In July 2002, a review of the strategy's achievements found that it had not succeeded in stemming the hepatitis C epidemic. It pointed to limited resources and lack of an implementation plan, inadequate research, rudimentary surveillance and an erosion of harm reduction through the maintenance of repressive drug laws and policies.

Wooldridge having left parliament, the federal government delayed until September 2003 its response to this review and a coordinated review of the strategies on HIV/AIDS and sexually transmitted infections. Although the government accepted in general terms the thrust of the review, it rejected a call for safe injecting rooms and drug law reform, reasserting its 'tough on drugs' strategy. Wooldridge was appointed to chair a rebaptised Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis, to which a representative of the Australian National Council on Drugs was added. On accepting appointment, Wooldridge stated that hepatitis C was 'an epidemic out of control [but] I believe Australia can lead the world in its response to hepatitis C, as we did with HIV/AIDS twenty years ago'.

Conclusion

A historical approach to the making of policy on HIV and HCV makes clear that, while they may be comparable as blood-borne viruses, the ways in which they were perceived at the time they arrived on the public agenda produced vastly different responses. While AIDS was seen by the affected community, the media and the government as a crisis, hepatitis C received little more attention than other chronic diseases.

Well before formal integration with HIV/AIDS institutions, hepatitis C policy inherited approaches worked out for HIV/AIDS – notably, a partnership of government, health professionals and affected communities, a commitment to harm reduction, programs based on research and surveillance and sensitivity to stigma and discrimination. These would have been inconceivable had the hepatitis C epidemic arisen outside the context of HIV/AIDS as a challenge to Australian health policy.

Nonetheless, the agendas and networks developed in response to HIV/AIDS left limited scope for a new focus on hepatitis C. On the other hand, the preference of governments for linking institutions and strategies for HIV and HCV was primarily aimed at cost-saving and may have damaged, or at least restricted, appropriate responses to each.

Precedents set in the funding of HIV/AIDS organisations and services raised expectations that HCV, with a much higher and rapidly increasing prevalence, would receive equivalent funding. Governments and the public, however, were never sufficiently concerned with HCV to commit the funding needed for implementation of HCV strategies.

Partnership was also a problem. While AIDS councils could claim without serious contradiction to speak for the population primarily at risk of HIV infection, AIVL and AHC, despite much imaginative work with very limited resources, had a much larger and more diffuse constituency. Through a sometimes uneasy relationship, they had some difficulty carrying the same representative credibility in an environment where the risk behaviour that most commonly led to hepatitis C infection remained an illegal and highly stigmatised activity. While partnership became an established reality among the different groups working on HIV/AIDS policy and programs, the stigmatisation of drug users persisted in health settings and elsewhere. Needle and syringe programs were successful in blocking transmission of both HIV and HCV, providing a major area of synergy. Given the Coalition government's orientation towards drugs, however, even these programs continue to be at risk.

Those working on hepatitis C often describe it as a 'second-class disease', referring to the low level of resources allocated to potentially the most costly infectious disease in Australia. They may be correct under the criteria of evidence-based medicine. But there is always an implicit, if not explicit, contrast with the response to AIDS, which became a cultural rather than only a health phenomenon with its public images, its quilts and an outpouring of art, theatre, fiction and heroic tales which hepatitis C is unable to generate.

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Gay men and the response: political, legal & health promotion perspectives

2

by **Tim Leach**

AIDS has had a devastating effect on the gay community. Of the 6,174 people who have died of AIDS in Australia, 5,274 reported a history of homosexual behaviour. Eighty-three percent of all Australians who have had an AIDS diagnosis similarly claimed a homosexual history, and homosexual sexual activity accounted for 85% of HIV infections diagnosed between 1997 and 2001. (NCHECR, 2002) And these are just the statistics. Somehow not even this data gives a proper indication of the personal toll. For a generation of gay men, their relationship with HIV/AIDS has been a reluctantly intimate one, and as a consequence of this intimacy, gayness has been a defining characteristic of the epidemic in Australia.

The response to the epidemic was built on the notion of ‘partnership’. This partnership – between government, the medical and research sectors, and the ‘affected community’ – has been another defining characteristic of the epidemic and a cornerstone of the response’s success. While ‘affected community’ has always been broader than gay men, it has never been possible to have the former without the latter and in innumerable ways gay men have shaped and driven the response. So, as gayness has been a characteristic of the epidemic, so too has it been a feature of the response.

Another feature of the response has been focus on creating an ‘enabling environment’. This has meant attention to the construction of a legal and policy framework to facilitate the response – an environment that supported HIV/AIDS prevention strategies and assisted in the delivery of care and support services.

The creation of an enabling environment required attention to the needs of affected communities, and from early on in the epidemic the gay community made a strong case for the linking of HIV/AIDS responses with the human rights of gay men: it was not possible to reach underground communities with safe-sex messages, people would not come forward for testing, you could not seek the help of gay men in a public health response, while rejecting their needs as a community.

It is appropriate then to reflect upon how these two features – ‘gayness’ and ‘enabling environment’ – worked in combination. Sometimes, government approaches to gayness and enabling environment were compatible, but it is clear that there should have been greater synchronicity more often, more completely and much earlier than was the case.

It is hard to know whether by alleging human rights violations a writer engages an audience or loses its interest. 'Human rights violation' is an emotive term. It is overplayed, used inaccurately and people are appropriately sceptical about its use. But if we accept that the human rights of gay men include entitlement to equal protection of the law and not to be subjected to government (or government-sanctioned) discrimination on the basis of homosexuality, then the success of the Australian AIDS response stands in stark contrast to the promotion of the human rights of gay men.

It seems odd that after being such fantastic partners in the AIDS response, after running countless public health initiatives with minimal resources, after so effectively utilising the skills of extraordinary men and women on minimal salaries, and having revolutionised the relationships between health stakeholders to the benefit of the general community, recognition of the human rights of gay men has taken so long. It seemed, to many gay men at least, that a war against AIDS must be a war against prejudice and that your partners in one battle would be your partners in the other.

The legal framework

There are countless ways in which a government can promote equality for its gay citizenry, but some key indicators of its commitment to equality are the decriminalisation of homosexual activity, equal ages of consent for heterosexual and homosexual sex, anti-discrimination protections for gay men and legal recognition of same-sex relationships.

The best analysis of HIV/AIDS law and policy in the 1990s was the Australian Federation of AIDS Organisations' *HIV/AIDS Legal Guide*. It remains a valuable record of national human rights advancement. In 1991, the year the first edition of the guide was published, homosexual sex was still unlawful in Tasmania. Homosexual sex had only just become lawful in Queensland, with prosecutions in that state having occurred as recently as 1989. Unequal ages of consent existed in NSW, the Northern Territory, Queensland and Western Australia. State and territory police also used various public nuisance/gross indecency statutes to prosecute men for engaging in consensual homosexual acts. (Godwin, 1991: 165-181)

In that same year, only NSW and South Australia had legislation to protect gay men and lesbians from discrimination based upon their sexuality. Even in those states where the anti-discrimination provisions applied, they were invariably riddled with exceptions and dependent, as all complaints-based remedies are, upon the marginalised taking action against the empowered.

In 1991, there was no legislative recognition of same-sex relationships anywhere in Australia, even though AIDS was evidencing the need for this on an almost daily basis. Many gay men were excluded from their dying partners because they weren't deemed 'family', or received nothing from their partner's estate (nor in some circumstances did they receive their partner's ashes).

Step forward to 1993, the year the second edition of the guide is published, and homosexual sex remains unlawful in Tasmania. Three more Australian jurisdictions have sexuality-based anti-discrimination legislation, but the Commonwealth, Victoria, Tasmania and WA still do not. Unequal ages of consent remain in NSW, the Northern Territory, Queensland and WA. (Godwin, 1993: 210) There has been no change federally or in any state or territory on the issue of relationships recognition. In the world of law reform, two years is not such a long time, but in 1993 alone over 570 homosexual men died of AIDS, over 650 received an AIDS diagnosis and over 790 homosexually active men acquired HIV.

While some suggested that gay and lesbian law reform should be delayed while the community focussed on combating HIV/AIDS, the better view acknowledged that the one could not be separated from the other. By 1991, the national HIV/AIDS strategy already noted that laws regulating or penalising homosexual behaviour served only to impede public health responses and resulted in communities of homosexually-active men being driven underground, and away from testing, counselling and support services. (Commonwealth of Australia, 1989)

The Legal Working Party of the Inter-Governmental Committee on AIDS (IGCA) urged the introduction in each state and territory of equal opportunity legislation to protect gay men and lesbians from discrimination. (Watchirs, 1991: 32) The IGCA also called for legal recognition of non-traditional domestic relationships (including same-sex *de facto* relationships). This position was adopted partly in response to representations from AFAO that such a move would raise esteem within gay and lesbian communities and contribute to behaviour change, as well as lessen the financial and other burdens associated with non-recognition in the areas of superannuation, insurance, wills and intestacy.

NAPWA's¹ 1993 *Declaration of the Rights of People With HIV* also called for recognition of gay and lesbian relationships, as did the *Courage of our Convictions*, a 1994 report commissioned by the then NSW Health Minister to review implementation of the IGCA recommendations. (Leach, 1994a) Unfortunately, in 2004 these rights look even further from realisation, and things may even be going backwards. It is hard to view the recent federal parliament's move to codify the exclusion of gay and lesbian couples from the institution of marriage (*Marriage Amendment Act 2004*) as anything but a backwards step.

Gay and lesbian rights organisations understood the welfare of the community was as much dependent upon equality as upon strategies to keep core components of the community alive. There were ongoing campaigns for equality by the NSW Gay and Lesbian Rights Lobby, at a national level by the Australian Council for Lesbian and Gay Rights, and the Tasmanian Gay and Lesbian Rights Group's campaign to overturn that state's sodomy laws gained national and international attention with its successful case to the United Nations Human Rights Committee.²

The Sydney Gay and Lesbian Mardi Gras was a powerful annual statement about the 'otherness' (and continued marginalisation) of gay and lesbian Australia. This annual demonstration was a timely reminder of the size of the disenfranchised community and the crowds enjoying the spectacle were made aware of the interconnection of gay and lesbian rights issues with HIV/AIDS issues. These reform movements (or human rights movements, depending upon your preferred language) collaborated closely, acknowledging the interdependency of AIDS and gay/lesbian agendas.

During these times, AIDS councils were strong advocates of equal rights for gay men. AIDS organisations and gay/lesbian organisations collaborated on a range of reform campaigns. In Sydney, epicentre of the epidemic, one of the best examples of collaboration was in relation to an overhaul of NSW's antiquated *Anti-Discrimination Act 1977*. Behind-the-scenes lobbying gave way to angry demonstrations and when, in 1993, the NSW government sought to placate the gay and lesbian community by offering vilification protections for people with HIV/AIDS, campaign organisers (including the Gay and Lesbian Rights Lobby and the AIDS Council of NSW) rejected this until the offer would include vilification protections for gay men and lesbians also. (Blair, 1993; Leach, 1993)

Jump forward to 2004: recent reform in NSW and WA has meant that gay men in these jurisdictions enjoy the same state sanction for their consensual sexual activity. There is now sexuality-based anti-discrimination legislation in each state and territory. There has been significant progress in the area of relationships recognition, with the ACT having paved the way for reform in NSW and other states.³ Tasmania has enacted its own legislation to afford recognition of same-sex and other significant personal relationships and permit same-sex couple adoption in certain circumstances. (Mills, 2003)

Still, there remains significant reform outstanding. Anti-discrimination remedies are important and valued, yet a collective analysis of state Acts indicates a pattern of reluctant and deceptive reform – loopholes include exemptions for areas such as private schools, religious organisations, small employers, and (perhaps most offensive of all) employers of positions that involve work with children. Even if gay men and lesbians are discriminated against in an area covered by a state Act, administrative delays, low awards and the personal demands of being a complainant in a highly scrutinised jurisdiction militate against use of these avenues of redress.

Relationships are not recognised for all purposes. Despite the extent of reform in NSW, not all entitlements under industrial legislation are available to an employee's same-sex partner. With the exception of Tasmania's recent reforms, same-sex partners are still not permitted to adopt as couples, but only as individuals (consequently lower down the hierarchy of eligibility).

There continues to be an incapacity to acknowledge the reality of same-sex couples and their parenting arrangements with laws that, for example, declare a child conceived (through assisted reproductive technology with donor sperm) by a woman with the consent of her female partner to have only one legal parent, in contrast to the child of a woman who conceives (through assisted reproductive technology with donor sperm) while the partner of a man, has two parents.

There is also still no national anti-discrimination legislation. Apart from the value of having a strong national statement on sexuality, there are key areas of life that can only be covered by national legislation, including the employment and service practices of some Commonwealth instrumentalities, and superannuation. Given the difficulties gay men have experienced during the epidemic of extracting legitimate superannuation entitlements from the funds of deceased partners, the superannuation industry might well benefit from some anti-discrimination law coverage.

Health promotion

The lack of an enabling environment makes education work more difficult.

Reflections on health promotion initiatives should note the ingenuity and creativity of gay men working as AIDS council educators – and the many artists contributing to safe-sex education from outside of AIDS councils. Out of the crisis emerged some educative images that were beautiful, clever, funny, irreverent and, most importantly, effective. It's a credit to councils and their AIDS response partners that so many of the early campaigns were so sexy, or at least, so sexually graphic. It made sense, of course, to use sex to sell messages about sex, but the bluntness of the imagery and message must have caused many a bureaucratic migraine – and lots of bureaucrats (and politicians) went out on a limb to approve such material. At a broader level, the partnership offered forums in which government and community could negotiate about imagery, and the Commonwealth Parliamentary Liaison Group enabled political sensibilities to be, for the most part, effectively managed.

However, many campaigns ran into difficulty. For example, the Victorian AIDS Council's 1990 'When you say yes, say yes to safe sex' campaign, which featured two young gay men kissing, was seen by the Victorian government to have gone beyond tolerance of homosexuality to promotion. (HIV/AIDS Legal Link, 1990) In 1995, the Queensland AIDS Council's 'Bubble Boy' campaign was banned by Queensland and Commonwealth authorities for its alleged appeal to impressionable young men. (Kennedy, 1995) The Queensland government banned the 'Multicultural Sexual Health Calendar' and the 'Do Choose Enjoy' campaign in 1996. (Selvanera, 1996)

These responses, and there were many more examples, reiterated that homosexuality was tolerated but discouraged, acknowledged but not preferred,

permitted but not a right. As a policy framework, this is not conducive to conveying public health messages. These same policy challenges exist today in acknowledging the sex lives of people with HIV/AIDS (begrudgingly permitted, but never as a right).

Caught between a conservative society and constant pressure from a discerning audience to come up with newer, brighter, cleverer education messages, it can't have been easy for AIDS educators. Within this demanding context, educators moved backwards and forwards in their understanding of the relationship between gayness and HIV/AIDS. Some of the earlier messages sought to assert the gayness of the epidemic – to use images with meaning to gay men when more sedate campaigns might have been preferred by other members of the partnership.

But having succeeded in making AIDS messages gay, educators then had to struggle to place these AIDS messages within broader constructs of gayness. As the epidemic changed, and gay men's experience and attitudes evolved, there emerged a need to reposition the virus within the context of gay men's lives – to be less didactic and encourage gay men to reflect upon the nature of their relationship with HIV, and the place of the virus within their world. In the end, it has perhaps become the case that the relationship is best represented not by circles within circles but by a Venn diagram – separateness in part, overlap in part.

These struggles were reflected in the interaction between gay men's education (prevention) and education for people with HIV/AIDS (care and support). Once unconditionally separate, there developed acknowledgement that the two shared the same continuum – that prevention and positive education remained separate to their mutual peril.⁴ This acknowledgement required, among other things, an understanding of the (politically challenging) fact that positive gay men have sex lives, and consequently ongoing HIV prevention and sexual health promotion needs, as well as educational needs relating to treatment, care and support. This understanding was reflected in a range of *National AIDS Bulletin* covers depicting sexualised images of HIV-positive men.⁵

Where the link between prevention and care has been acknowledged, it has led to improved prevention campaigning, the skilling-up of care and support workers and enhanced attention to the health information needs of positive people. It leaves some uncertainty around who should be doing what – while the continuum is a reality, AIDS councils and people living with HIV/AIDS (PLWHA) groups remain in many jurisdictions quite separate agencies. The community AIDS sector's commitment to community development and consumer involvement warrant enhanced roles for PLWHA agencies in the delivery of positive education, but few PLWHA organisations seek specific prevention education missions. Still, AFAO and NAPWA have modelled good responses to this challenge at national level.

Human rights

Trying to present the response as an issue of human rights begs the question as to what extent it has forged, or at least contributed to, a broader human rights movement within Australia. The epidemic made natural partners of the marginalised: people with the virus, gay men, sex workers, injecting drug users and Indigenous Australians. It brought people with HIV/AIDS into alliances with other disability groups around issues such as health care and disability discrimination.

It wasn't always an easy alliance between AIDS organisations and other disability groups. The AIDS movement was more comfortable with rights-based approaches than many other disability groups. But rights enforcement is not always easy when a disability prevents (or is used as the pretext for preventing) participation in community life. Many AIDS activists and advocates were so effective because they had enjoyed access to influence and privilege and were able to use these experiences in demanding their 'place at the table'. Many other disability groups were run by people who had spent a lifetime outside the mainstream and for whom a place at the table was a much greater challenge. There was resistance on both sides – no doubt some disability movements were put off by the gayness of AIDS, and positive people put off by the image of disability as dependent, unemployed and non-strategic.

The *Disability Discrimination Act 1992* (DDA) not only grouped disability communities within the definition of 'disability', but also came with a forum in which to gather and influence government – admittedly in the form of the rather sympathetic Human Rights and Equal Opportunity Commission (HREOC). It's to the credit of HREOC's then employees that initiatives to build awareness of the new DDA were so pointedly inclusive of HIV/AIDS, and of gay men and lesbians. HIV-positive people were amongst the first DDA complainants, and one of HREOC's earliest DDA decisions was one in favour of an HIV-positive soldier who had been discriminated against by the Australian Defence Forces⁶ – although in the end, the decision was overturned. Other bases for alliance included the reality of gay men and lesbians with disabilities other than HIV/AIDS – and in this context the pioneering work of deaf gay men stands out – and the particular HIV prevention needs of some people with disabilities; people with intellectual disabilities, for example, require creative awareness interventions from AIDS council educators.

However, there was no community rights-based alliance able or willing enough to defend HREOC against large-scale Commonwealth government funding cuts in 1997, or to defend the Anti-Discrimination Board (ADB) from similar cuts by the NSW government in 2003. It is not clear though whether these failures reflect upon the Australian human rights movement in general, or indicate a frustration with the inadequacies of the HREOC and the ADB models. Where rights must be enforced through government-funded statutory authorities, long delays,

low awards and (depending on the jurisdiction) difficulties with enforcement of decisions are not uncommon. Perhaps it is time then for alternatives to the traditionally weak statutory rights body – time for something with teeth. But that would require a genuine belief in human rights as a vehicle for improving the lives of ‘ordinary Australians’. No such belief is currently apparent.

The AIDS sector’s mastery of the rhetoric of rights was matched by its understanding and use of the language of community development. In general, community-based AIDS agencies did community development well, and when in 2000 AFAO reallocated to NAPWA a portion of its resources – in accordance with its new strategic plan that emphasised the centrality of positive people – this seemed community development in action. But it is questionable whether sex worker organisations or injecting drug user organisations would, at state or national level, consider that everything possible had been done to develop their community responses. Certainly, prior to the emergence of hepatitis C, user groups everywhere struggled to obtain the funds necessary to support their engagement in AIDS responses. The national sex worker peak organisation, Scarlet Alliance, is still unfunded.

In its work with Indigenous communities, the community AIDS sector has again had its commitment to community development principles tested. Much of the work done by AFAO and AIDS councils in Indigenous health has been of high quality, and to this end, AIDS organisations have been well-served by Indigenous gay men and sistergirls who have managed to simultaneously navigate white organisations and the complexities of Indigenous politics.

AFAO has conducted national conferences and state AIDS councils have developed some fantastic education campaigns. At a broader level, AFAO and the National Aboriginal Community Controlled Health Organisation (NACCHO) struck a Memorandum of Understanding in 1999, and AFAO placed land rights, self-determination (through support for the Aboriginal and Torres Strait Islander Commission and NACCHO), and the health of Indigenous people firmly within its advocacy brief.

But perhaps the real community development tests will revolve around the establishment of queer Indigenous community organisations or the handing over of Indigenous AIDS programs to Indigenous health organisations. These will be complex developments – despite great gains, racism within AIDS councils and homophobia within Indigenous organisations remain issues – but a rights-based framework will continue to offer the best context for future collaboration.

Australians understand and value a ‘fair go’. True, this is an elastic term and subject to some exploitation, but at its heart this is a concept not far removed from acceptance of the importance of human rights. While we understand the former better than the latter, and human rights are more fundamental and less subjective than a fair go, the one can be a vehicle for understanding the other. In

its simplest form, most people would agree that people should not be subjected to government discrimination on the basis of irrelevant characteristics. This is why the arguments of AIDS exceptionalism were always misleading – in terms of enabling environment, gay men sought only what others had already.

The communities most affected by HIV/AIDS did gather effectively around rights issues in building the enabling environment we enjoy today, and this collaboration could be a solid basis for the building of a broader human rights movement. A national rights-based movement that used the lessons learned through the AIDS response, one taking up the claims of *all* marginalised communities in Australia would be a fitting tribute to those who have lost so much in the struggle. True, there are some battles to be won that are specific to the rights of gay men and lesbians, but this law reform work will be enhanced by attention to the rights of other groups as well. As it turns out, gay men have some recent experience fighting on simultaneous fronts, and as we have learned from AIDS, at least it's the same war.

For the past decade, Tim Leach has worked for a range of community-based AIDS organisations and human rights agencies, including ACON, the Australian Federation of AIDS Organisations, the Human Rights and Equal Opportunity Commission and the NSW Anti-Discrimination Board. He has been a member of the Gay and Lesbian Rights Lobby Committee and is a former-convenor of the Lesbian and Gay Legal Rights Service.

Notes

- 1 National Association of People Living With HIV/AIDS.
- 2 See in particular *The Bride Wore Pink: Legal Recognition of Our Relationships: A Discussion Paper* (Gay and Lesbian Rights Lobby, 1993) and *The Bride Wore Pink II: A Discussion Paper* (Gay and Lesbian Rights Lobby, 1994). See also Alexander (1994) for an analysis of the decision in *Toonen v Australia* CCPR/C/50/D/488/1992.
- 3 For discussion of *Domestic Relationships Act 1994* see Leach (1994b)
- 4 The AFAO/NAPWA Positive Information and Education Project – through its national consultations and consequent strategy – paved the way for this revolution in education practice.
- 5 For example, *National AIDS Bulletin*, Vol. 8, No. 2, March 1994.
- 6 *X v Department of Defence*, Human Rights and Equal Opportunity Commission, No. H94/98, decision dated June 29, 1995.

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Australia's response to HIV among injecting drug users: the band is still playing

by Alex Wodak

This chapter is dedicated to the memory of Dr Margaret MacDonald whose development of an outstanding system of surveillance for blood-borne viral infections among injecting drug users contributed substantially to public health in Australia and other countries. Dr MacDonald died after a brief illness in September 2003.

The gathering storm

Soon after the AIDS epidemic was first officially recognised on 5 June 1981, it was recognised that injecting drug users were at risk of contracting and presumably transmitting the new and mysterious disease. (Shiltz, 1999) Within a few years of the development of a serological test for demonstrating exposure to HIV, evidence began to accumulate that substantial proportions of injecting drug users in many cities in the US and Western Europe were already infected. Some concluded that Australia was also at risk of an HIV epidemic beginning among injecting drug users and then possibly spreading to the general community. Official AIDS bodies in Australia at the time were under no illusions about the seriousness of this threat, but elsewhere there was little interest and some resistance to the notion of taking this threat seriously until the spring of 1985. A visit to Australia by Dr Jim Curran of the US Centers for Disease Control in 1985 appears to have influenced many in Australia to not repeat the tragic policy errors that had been made in the United States.

Australia's response to this impending threat cannot be understood without some knowledge of the global drug prohibition system. (Bewley-Taylor, 2001) Like most other countries, Australia drifted into the slowly evolving global prohibition system as this developed during the twentieth century. (Manderson, 1993) In the first half of the twentieth century, heroin could be prescribed lawfully. Cannabis began to be prohibited by the states after Australia attended a League of Nations meeting in Geneva in 1924-25. The prohibition of heroin in Australia in 1953 (Manderson, 1993) followed pressure from the World Health Organization (and probably originally from the US, although this has never been confirmed).

Heroin injecting only became apparent in the late 1960s but increased steadily over the following decades. (Law, 1999) A variety of other drugs then also became available. With growing numbers of Australians using larger quantities of illicit drugs of ever-increasing variety and with rising numbers of drug-related deaths and crime, major parliamentary enquiries and royal commissions were held frequently. Initially, these official enquiries called for 'more of the same', but there has been a tendency over time for more recent enquiries to acknowledge the conspicuous lack of success and call for more pragmatic responses. Royal Commissioner Justice James Wood concluded, 'It is fanciful to think that drug addicts can be prevented from obtaining and using prohibited drugs'. (Wood, 1997)

It was estimated that commonwealth and state governments in 1992 expended A\$461 million in response to illicit drugs, with 84% allocated to supply control, 6% to treatment and 10% to prevention and research. (Collins and Lapsley, 1996)

The global drug prohibition system developed from an international meeting convened by the US in Shanghai in 1909. (Bewley-Taylor, 2001) Many other meetings followed, culminating in international drug treaties in 1961, 1971 and 1988. (Bewley-Taylor, 2001) These treaties provided for a network of international agencies within the United Nations system charged with monitoring and implementation responsibilities. About 170 countries ratified and endorsed the three treaties.

Harm minimisation

In 1984, the Opposition Leader, Andrew Peacock, asked the Prime Minister, Bob Hawke, whether he had declined to provide further funding to the Costigan Royal Commission because he was too close to drug traffickers. Hawke's tearful response to this question puzzled the nation until Hazel Hawke explained that their daughter was addicted to heroin. Therefore, she explained, any allegation that her husband was connected to drug trafficking was the most wounding insult imaginable. The nation was stunned. Later the Prime Minister responded to a question on radio by announcing that if his government was returned at the forthcoming elections, a major initiative on drugs would be developed.

The Hawke Labor government was returned at the 1985 election, though with a reduced majority. Bob Hawke invited all six Premiers and both Chief Ministers to a Special Premier's Conference ('the Drug Summit') in Canberra on 2 April 1985. It was said to have been the first time that the Prime Minister, all Premiers and both Chief Ministers had met since the Second World War to discuss any matter other than financial matters. There was universal support that day for the proposal to adopt harm minimisation as the nation's official drug policy (although the term 'harm minimisation' was not defined). The summit also agreed to support a comprehensive package of policies entitled 'the National Campaign against Drug Abuse' (NCADA, later re-titled 'the National Drug Strategy').

Harm minimisation has remained Australia's official national drug policy ever since. The machinery developed at the time of the establishment of the NCADA included the Ministerial Council on Drug Strategy (MCDS). This comprised the eight state and territory Police Ministers, the Commonwealth Justice Minister and all nine Health Ministers. MCDS has been recognised as Australia's paramount drug policy-making body since 1985. It meets at least once, sometimes twice, a year. MCDS has endorsed harm minimisation on several occasions since 1985. On each occasion, a review of Australia's drug policy by independent evaluators has recommended that harm minimisation should be re-endorsed and extended. Several of these evaluations recommended the adoption of a new definition of harm minimisation.

During the Howard government, harm minimisation later came to be defined as efforts to reduce supply, reduce demand and reduce harm. However, the International Harm Reduction Association defines harm reduction as 'policies and programs which attempt primarily to reduce the adverse health, social and economic consequences of mood altering substances'. (IHRA, 2003)

Needle syringe programmes

In 1985/1986, the NSW Health Department declined to approve numerous submissions by this author requesting permission to establish an official pilot needle syringe programme. In response, my colleagues and I established an unofficial pilot needle syringe programme in Darlinghurst on 12 November 1986. This unleashed a national avalanche of fierce controversy.

The NSW Health Department approved a state pharmacy scheme within weeks and the first needle syringe programmes independent of pharmacies were established in early 1987. Within a couple of years, all states and territories established needle syringe programmes. The authorities also expanded these programmes, rapidly reaching an annual turnover of 30 million sterile needles and syringes by the turn of the century.

In hindsight, this was a remarkable and courageous period of state and federal policy-making, although at the time it seemed recklessly slow. There is little doubt that health authorities in 1985 had more policy flexibility than existed previously because harm minimisation had already been adopted as Australia's official national drug policy. Fortunately, the authorities were prepared to adopt needle syringe programmes in advance of any existing evidence that they were effective, safe and cost-effective. Critics asserted that needle syringe programmes would increase injecting drug use.

Evidence to support sterile needle and syringe programmes did not take long to accumulate. By the early 1990s, the evidence was already powerful, but perhaps not watertight. Before the end of the decade, the evidence clearly supported the effectiveness of needle syringe programmes in preventing HIV spread (Gibson, 2001).

A study commissioned from independent and reputable researchers analysed 778 calendar years of data from 103 cities worldwide (Health Outcomes International, et al, 2002) and found that the mean HIV prevalence increased in cities without needle syringe programmes by 8.1% and decreased by a mean of 18.6% in cities with needle syringe programmes. Applying these results to Australia, needle syringe programmes had prevented 25,000 HIV infections and 21,000 hepatitis C infections by 2000 and saved 4,500 AIDS deaths and 90 hepatitis C deaths by 2010. By 2000, the needle syringe programmes had cost Australian governments A\$130 million and saved between A\$2.4 billion (at 5% annual discount) and \$7.7 billion (without any discount).¹

By any measure, programmes to sell, distribute or exchange sterile needles and syringes for the purpose of reducing the spread of HIV and other blood-borne viral infections would be classified as harm reduction or minimisation. The evidence at the turn of the century was now compelling that needle syringe programmes were effective, safe and cost-effective. Australian injecting drug users were estimated to share with an average of six partners a year, with less than seventeen partners a year needed to maintain low HIV prevalence and less than three partners a year required to achieve minimal hepatitis C infection. (Murray, et al, 2003)

Methadone and other treatment programmes

Dr Stella Dalton established the first pilot methadone programme in Australia in 1969. The following year, this programme of subsidised and organised treatment was declared official. By 1985, about 2,000 Australians were enrolled in methadone programmes. Less than 20 years later, about 35,000 Australians were enrolled in methadone treatment. In 2000, buprenorphine was provided as an alternative to methadone for the first time.

There has been a substantial improvement in the quality as well as the quantity of the methadone programmes in Australia. The rapid expansion of methadone programmes in Australia from 1985 was carried out in the belief that this treatment would reduce the spread of HIV infection among injecting drug users. By the end of the century, 34 studies had been published which supported this hypothesis. (Gibson, 1999) Yet methadone treatment continues to be criticised.

Educating drug users about HIV

The first attempt to educate injecting drug users in Australia about the new era of HIV infection appeared in about 1987 and featured the simple words 'never, ever, share needles and syringes'. Even this modest wording caused controversy. Critics argued that the advertisement should simultaneously advocate abstinence from illicit drug use and vigorous efforts to reduce sharing to avoid HIV infection.

However, a new era of explicit advertising began. Campaigns often involved injecting drug users extensively in the design and implementation of the campaigns. The advice provided by injecting drug users to advertising agencies and government departments helped to maximise the effect of these campaigns on behaviour change.

User groups

The NSW Users AIDS Association (NUAA) was established in 1989 with funding from the NSW Department of Health. This funding has been continued without interruption ever since. NUAA may well be one of the largest government-funded user groups anywhere in the world. By the turn of the century, Australia had a government-funded user group in each state, both territories and also a national body.

Experience has shown that these user groups have played a critical role in the partnership between government officials, affected communities, clinicians and researchers. On a number of occasions, user groups have collaborated effectively with law enforcement bodies. For example, user groups discussed arrangements for police and ambulance officers called to drug overdose incidents. Guidelines developed from these discussions helped police and ambulance officers and also assisted efforts to reduce drug overdose deaths.

Responding to hepatitis C

The first antibody test for hepatitis C was developed by 1988 and began to become available in Australia in the early 1990s. As in other countries, surveys demonstrated a very high prevalence of hepatitis C among injecting drug users in Australia. Estimates of the number of injecting drug users infected with hepatitis C increased from 11,000 in 1997 to 16,000 in 2001. (Law, et al, 2003) Annual surveys of injecting drug users attending needle syringe programmes began in 1995 (MacDonald, et al, 2000) and these initially showed a decline in prevalence of hepatitis C, but prevalence has been increasing in recent years.

Australia's admirable response to HIV is often compared to the response to hepatitis C. While the response to HIV has undoubtedly been more effective and more impressive, Australia did respond to hepatitis C earlier and more vigorously than most other countries. In addition, many of the measures adopted to control HIV among injecting drug users had been expected to also control hepatitis C, as both viruses are spread by blood-blood contact.

It is now generally accepted that the response to hepatitis C has been less effective for several reasons. First, it is known from studies of stored plasma that hepatitis C was already prevalent among injecting drug users in the early 1970s (Moaven, et al, 1993), whereas harm-reduction measures to control HIV among

this population only began to be implemented in the late 1980s. Second, blood-blood spread of hepatitis C is an order of magnitude more infectious than HIV.

More than 200,000 Australians have been exposed to hepatitis C. (Law, 2003) About 90% of these have been exposed through the sharing of needles and syringes or other injecting equipment. Drug injecting is so inherently risky for hepatitis C, that it will be very difficult to reduce the incidence and prevalence of hepatitis C while there is such a large and growing pool of injecting drug users in Australia. (Wodak, 1997)

Australia's level of implementation of needle syringe programmes, methadone programmes, explicit and peer-based education and community development of injecting drug users remains close to world's best practice. Nevertheless, hepatitis C continues to spread extensively within this population.

It is likely that a high incidence and prevalence of hepatitis C will continue unless and until the pool of injecting drug users begins to decline substantially. This will either happen because the availability of injectable drugs declines or more probably, if drug users in large numbers begin to consume potentially injectable drugs by non-injectable routes of administration. (Wodak, 1997) High street prices and low purity of street drugs, generally considered to be indicative of effective supply control, militate against non-injectable routes of administration. In addition, heroin supplied to the Australian market arrives as the salt, heroin hydrochloride, which is highly soluble and therefore far easier to self-administer by injection than inhalation of vapour.

The illicit drug market

Heroin production and importation were first prohibited in Australia in 1953. (Manderson, 1993) At that time, there were very few heroin users. The number of heroin injectors in Australia began to increase in the late 1960s during the Vietnam War, after the arrival of large numbers of US servicemen in eastern seaboard capital cities on five days rest and recreation leave. They introduced some young Australians to heroin and the practice of injecting. The number of heroin injectors in Australia has increased inexorably ever since. (Law, 1999) It was estimated that the growth in the number of drug injectors in Australia was about 7-8% per annum for the last three and a half decades.

The National Crime Authority Commentary in 2001 noted 'in the year 1999/2000 Australian law enforcement agencies seized ... approximately 734 kilograms of heroin. Prior to its disbanding, the National Crime Authority estimated that this represents just 12% of heroin being consumed'. Understandably, the National Crime Authority Commentary concluded: 'experience should encourage us not to rule out consideration of new options or reconsideration of options previously deemed unpalatable ... Among the many measures worthy of consideration is to control the drug market for addicts by treating the supply of addictive drugs

to them as a medical and treatment matter subject to supervision of a treating doctor and supplied from a repository that is government controlled.²

An ever-increasing range of different types of illicit substances accompanied the relentless rise in the number of drug users and quantity of drugs imported. There has been a slow transition from plant-based drugs such as heroin to chemical-based drugs such as ATS. It is easier to evade detection when trafficking plant-based drugs as these have a shorter supply line. Following the introduction of precursor controls intended to limit amphetamine production in Australia, producers simply shifted to ephedrine precursors. Consequently, production now universally ends up with methamphetamine. There is increasing concern about mental health problems and the propensity for violence and unsafe sexual behaviour among ATS consumers.

In the last months of 2000, the heroin glut came to an end in Sydney. A scarcity of heroin was soon reported in other parts of the country. The street price of heroin increased and the purity of street heroin began to decline. Drug users reported spending more time searching for heroin. Noting that a heroin shortage had not been reported at that time in any other country, the Federal government claimed that their 'Tough on Drugs' policy adopted in 1998 had produced the heroin shortage by increasing the effectiveness of domestic law enforcement. However, the increase in the quantity of heroin seized (despite a decline in the number of seizures) was insufficient to explain the heroin shortage. Some senior law enforcement officers publicly dismissed the claims that the heroin shortage had resulted from more effective supply control.

It is more likely that the heroin shortage resulted from a combination of factors. First, a drought in Myanmar since the mid-1990s had resulted in a two-thirds reduction in opium production. Second, following the retirement of the Burmese opium warlord, Kun Sa in 1996, drug traffickers in Myanmar partially switched production from opium to ATS. Third, increasing consumption of heroin in China and other parts of Asia resulted in heroin which may have been intended for the Australian market being diverted elsewhere. Two intelligence analysts in Australia in the 1990s predicted a forthcoming heroin shortage because of rapidly increasing heroin consumption in China. A kilogram of heroin increases in price more than two hundred fold journeying from Bangkok to Sydney. When the risks of detection are increased or penalties of conviction made more severe, the price and profits are increased to compensate.

Whatever the causes of the heroin shortage, there has been concern that the switch from heroin injecting to injection of psychostimulants (ATS and cocaine) increased the prospects of more blood-borne viral infections (such as HIV or hepatitis C) as some psychostimulant users inject more than 20 times a day in short bursts.

After about 18 months of the heroin shortage, the availability of heroin began to increase again. However, by the end of 2003, heroin availability has still not reached levels seen before the start of the shortage.

Evolution of harm minimisation

There is no doubt that the epidemic of HIV/AIDS involving injecting drug users increased the support for and interest in harm minimisation.

Attempts to protect public health in Australia by controlling HIV among and from injecting drug users ran head-on into an entrenched system designed to protect supply control at all costs. This was for many a significant learning experience. The success of efforts to control HIV in this population, using harm minimisation principles, contrasted with the lamentable results in other countries, such as the USA, which explicitly rejected harm minimisation.

The first phase of harm minimisation involved efforts to reduce adverse health, social and economic costs without questioning the fundamentals of a drug policy founded on supply control. The second phase of harm minimisation extended this work by attempting to modify the basic harm-augmenting drug policy.

Increasingly, the distinction between harm reduction and drug law reform began to blur. In some countries, drug law reform seemed an impractical indulgence distracting precious energy and time from the urgent task of controlling an HIV epidemic. However, excessive reliance on law enforcement strategies produced a poor return on investment for taxpayers while health and social interventions, bringing a far better return, often received less funding.

Human rights

One of the many great legacies left behind by Dr Jonathan Mann was the teaching that human rights were the central issue of HIV/AIDS. Perhaps this is a lesson that had already been learnt in many previous public health disasters. The criteria accepted as defining human rights are often violated when dealing with injecting drug users. (Wodak, 1998) As is the case with other groups at higher risk of HIV infection, this has profound implications for HIV control. It is no accident that most of the groups at greatest risk of HIV are also subjected to intense discrimination. Successful attempts to control HIV among injecting drug users have generally relied on efforts to make this population part of the solution rather than remaining the crux of the problem.

Drug policy and the influence of HIV/AIDS

It is now almost 20 years since efforts began to prevent the threatened epidemic of HIV among injecting drug users in Australia. The success of these efforts in Australia and the contrasting failure in other countries with a zero tolerance

approach, prompted many to begin thinking about the way our community has responded to illicit drugs.

Much of the accumulated evidence has shown that the case for some reform grows ever stronger with the passage of time. In fact, the process of drug law reform is already under way. The modification of drug laws to permit the establishment of needle syringe programmes was part of this.

Cannabis laws in four Australian jurisdictions have been modified to introduce an expiation notice system. NSW has made a commitment to introduce medicinal cannabis. The decision in 1997 by Prime Minister Howard to over-rule the 6:3 decision by MCDS supporting a scientific trial of heroin assisted treatment did not indicate a new and permanent direction for drug policy. Hardly a month passes these days without one or more nations announcing a more health and social-based approach to illicit drug use. Evidence-based policies are much harder to sell politically because they sound counter-intuitive. But the strong empirical support for harm reduction and drug law reform is increasingly difficult to deny.

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Notes

- 1 By convention, future savings to governments are discounted at 5% annually so that a \$100 million bridge, which is estimated to save \$10 million a year, will be estimated to save \$10 million in 2004/05, \$9.5 million in 2005/06, \$9.025 million in 2006/07 and so on.
- 2 This quote was taken from the NCA web site which has since been taken down when the NCA was disbanded in 2002.

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Discrimination and hepatitis C



by Stuart Loveday, Carla Treloar, Catriona Elek, Maureen Steele, Max Hopwood

Introduction and context

In 1992, the Anti-Discrimination Board of NSW conducted an enquiry into HIV/AIDS-related discrimination, and found that for many people, prejudice and discrimination was so extensive that it was simply accepted as part of life, and people living with HIV/AIDS often felt powerless to do anything about it. (Anti-Discrimination Board of NSW, 1992) Almost a decade later, the same government agency conducted an enquiry into hepatitis C-related discrimination.

C-change, the report of the enquiry, noted that its readers would find the analysis of hepatitis C-related discrimination depressingly familiar – that the mere substitution of hepatitis C for HIV/AIDS would show how little had changed and how much still needed to be done. (Anti-Discrimination Board of NSW, 2001) The report and its recommendations called for significant legislative, public policy and educational responses to address hepatitis C-related discrimination.

In calling our report *C-change*, what we are calling for is a major transformation in public policy – one which refuses to accept that discrimination is the inevitable companion of hepatitis C infection and one which asserts that the level of hepatitis C-related discrimination which this Enquiry has identified cannot be tolerated any longer. (Anti-Discrimination Board of NSW, 2001)

A national needs-assessment of people living with hepatitis C carried out in 1996 found that the great majority of participants in the study had experienced serious discrimination related to hepatitis C. The groups most frequently identified as discriminating against people with hepatitis C were staff in health care settings, including doctors, nurses, ancillary staff, dentists and dental nurses and employers. (Burrows and Basset, 1996) This has been demonstrated in other Australian and international research. (Zickmund, et al, 2003; Crofts, et al, 1997; Hopwood and Treloar, 2003)

Similarly, the *C-change* enquiry found that health care settings were the most commonly reported context for hepatitis C discrimination. The evidence demonstrated that such discrimination undermines the relationship between people with hepatitis C and health care professionals, and often deters people from accessing health care services. Clearly, this has significant ramifications for the health and well-being of people with hepatitis C and undermines prevention efforts. (Anti-Discrimination Board of NSW, 2001)

A follow-up national needs-assessment carried out by the Australian Hepatitis Council in 2003 found that despite major developments in Australia's response to hepatitis C in recent years, for many people with hepatitis C, little has changed to improve their quality of life. 'There has been little achieved in reducing the stigma associated with hepatitis C and many people still experience discrimination when disclosing their hepatitis C status both in social settings and while accessing health care and other services'. (Australian Hepatitis Council, 2003)

Both federal and state and territory legislation prohibits discrimination against people with disabilities (and in this context hepatitis C and HIV/AIDS are each defined as disabilities).¹ These laws are perhaps the basic foundation of a social system that protects people's rights in a wide variety of public life, including employment, education, provision of goods and services and accommodation. However, it is critical to note that within this legislative framework, the burden is placed on individuals to enforce their rights. The impact of this is explored in the following section.

Arguably the most important consideration informing the approach we must take in order to tackle discrimination relies on the fact that, like health and illness, drug use and abuse are social constructs. As community approaches to health and illness change over time, so do attitudes to drug use. (Anti-Discrimination Board of NSW, 2001)

The *C-change* enquiry found that discrimination against people with hepatitis C is often motivated by two factors. The first is that discrimination is often the result of stereotyped responses towards people on the basis of past, current or assumed injecting drug use. Second, discrimination is often driven by irrational fears about hepatitis C infection, due to an inadequate understanding of how hepatitis C is transmitted. (Anti-Discrimination Board of NSW, 2001)

Effective education campaigns and strategies – and the heightened public awareness which may result – can contribute greatly to improved understanding of basic facts about hepatitis C transmission, thereby reducing discrimination caused by irrational fear of infection. However, it could be argued that discrimination based on the association of hepatitis C with illicit drug use is the more common root cause of hepatitis C-related discrimination. The illegality of the risk behaviour that most commonly leads to hepatitis C infection makes it difficult to address hepatitis C-related discrimination.

In contrast, HIV is most commonly transmitted in Australia through sexual contact between men. The decriminalisation of homosexual sex sent a clear public signal that a particular kind of discrimination was no longer acceptable and was formally rejected by national and state leaders charged with making laws and public policy. (Anti-Discrimination Board of NSW, 2001)

Until such time that laws and attitudes about injecting drug use change to view drug use primarily as a health concern rather than as a criminal or socially deviant

act, we will probably not see the sea-change that is required to bring an end to hepatitis C-related discrimination.

However, there is much that can be done through better community and professional education. Through more effective implementation of existing legislation, and repositioning of legislation to impose positive duties upon employers and service providers, a move away from the onus on the individual to take action can be facilitated.

This chapter sets out a conceptual overview of, and has a primary focus on, hepatitis C-related discrimination. However, it draws linkages to the lessons learned from discrimination pertaining to HIV/AIDS and refers to relevant areas of overlap. We have used the framework of the Ottawa Charter for Health Promotion as a basis for discussion and analysis in this chapter.

Because discrimination occurs in so many different ways and in so many different settings, the structure of this widely regarded charter provides a sound basis for examining the legislative, policy, human rights, ethical and educational components of responses to discrimination that have occurred to date. It also alerts us to strategies that could be considered for future management and education and ways of addressing and preventing such discrimination.

The Ottawa Charter defines health promotion as ‘the process of enabling people to increase control over, and to improve, their health’ and states that:

To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising personal and social resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being. (World Health Organization, 1986)

The charter emphasises that social justice and equity are fundamental prerequisites for health. The charter is constructed on five key principles for achieving healthy communities:

- Developing personal skills
- Creating supportive environments
- Reorienting services
- Strengthening community action
- Building healthy public policy

These principles enable us to validate and credit the experiences of individuals who endure discrimination, and provide a grounding for exploration of the impact of that discrimination at a broader level.

We will now explore each of the five principles of the Ottawa Charter to identify current and potential activities which contribute to or can ameliorate hepatitis C discrimination.

Developing personal skills

The focus of anti-discrimination laws in Australia is on an individual complaints mechanism. This process, however, puts the onus on individuals to recognise their negative experience as discrimination and have adequate resources and information to pursue an individual solution. This is problematic for numerous reasons, including that those most likely to be discriminated against are often the most marginalised. They are therefore the least likely to trust or make contact with complaint bodies, and will have least access to resources necessary to take action.

In addition, legal definitions of discrimination are limited in scope. They cannot account for discrimination outside of the legislation's defined settings, and are limited in their ability to address the full range of negative experiences and interactions which may stem from prejudice or stigma; interactions which may not strictly be discriminatory according to the law, but have impacts that are just as serious. Further, the Human Rights and Equal Opportunity Commission has been criticised for its unenforceable findings, delays in processing complaints and cost disincentives. This reinforces the need for these bodies to shift the balance of emphasis away from individual solutions to mechanisms which address systemic issues of discrimination. (Cabassi, 2001)

These criticisms propose a number of ways in which individuals could be better supported to work within the current legal framework. These strategies can be examined at the personal level, but are also implicated in other sections of the Ottawa Charter.

For example, community programs to build awareness of hepatitis C and associated discrimination may assist individuals with hepatitis C to recognise their experience as discrimination and help them to become sufficiently skilled and empowered to disclose their experience to appropriate referral agencies. A recent publication by the Australian Hepatitis Council, *My Rights*, is a step in this direction. Health workers, or other professionals, in regular contact with people with hepatitis C, their families or carers, could be supported through workforce development programs to, in turn, support individuals to use existing avenues of legal redress to discrimination. At the policy level, public enquiries, such as the *C-change* enquiry, could be used as leverage to change legal frameworks that facilitate individual complaints.

Creating supportive environments

There are numerous environments in which discrimination occurs that can be the focus of anti-discrimination action. We can examine, for example, the general community, workplaces, treatment centres and educational institutions. In these social and physical environments, the processes by which attitudes and policies come to structure the responses to hepatitis C and HIV are also important.

In terms of the general community, hepatitis C does not have ‘champions’. Unlike HIV, which attracted a host of celebrity endorsements and spokespersons, the hepatitis C ‘community’ remains, at best, relatively invisible to the general public. At worst, castigation of people with hepatitis C from the general community is generated from media reporting of the disease and injecting drug use.

For example, in a recent study of the local media around the closure of a Sydney needle and syringe program (NSP), the issue of hepatitis C and the profile of the clients of that service were consistently absent from all reporting. (Korner and Treloar, 2004) To counter uninformed or incorrect media coverage of hepatitis C and related issues, the Australian Hepatitis Council has produced a specific media guide. The guide provides access to relevant information and an overview of the challenges facing government and community responses to hepatitis C. (Australian Hepatitis Council, 2001)

The health care environment is one sector documented as a major source of hepatitis C-related discrimination. (Anti-Discrimination Board of NSW, 2001; Hopwood and Treloar, 2003) Aside from the policies which direct the overall operation of health care institutions, the workforce within these institutions is of interest as potential contributors to hepatitis C-related discrimination and as agents of change within institutions.

A workforce development project working with health care workers to ensure practices and policies comply with anti-discrimination laws was conducted by NSW Health Department in 2003. (Wilkins, 2003) This program sought to bring workers from area health services to consider hepatitis C discrimination at the local level and assist them in ways to prevent it. The individuals participating across NSW represent only a small fraction of the total potential health care workforce, yet based on their experiences in this program they could be considered as local ‘champions’, or agents of change, to challenge discrimination within their local context. In addition, drug user groups often run ‘attitudes and values’ training for professionals to help them to explore their own beliefs around drug use and hepatitis C.

As with most other experiences of health, ill-health and disease, hepatitis C can be both a product and cause of social and health inequalities. Awareness of the impact of social inequalities and determinants of health has gained momentum over the last decade or more.

The notion of social inequalities has a further role in exploring the impacts of health-status related discrimination which can serve to broaden the inequalities between those with and without chronic illnesses, such as hepatitis C, which are intimately linked in the public’s mind with reckless and feckless personal lifestyle choice. (Jarvis and Wardle, 1999)

This approach suggests that individuals who suffer ill-health as a result of drug use are to blame for their situation, and are less deserving of health care services.

This assumption ignores the quantities of evidence that demonstrates that drug use (both licit and illicit) is higher among groups with multiple disadvantage. This assumption also ignores the outcome of illicit drug use for some: that illicit drug use can further marginalise and disadvantage people. Living with hepatitis C can even further marginalise and disadvantage people as their state of health limits social contacts. Discrimination can compound marginalisation, as individuals may withdraw from social or service settings for fear of future episodes of discrimination.

The physical environment is also a space where normalising of the experience of hepatitis C could occur to lessen related discrimination. Structures of and within our physical environments could be re-oriented to prioritise the prevention of the disease, as a public health priority.

Without such acknowledgement, physical structures, such as supervised injecting centres, distribution and collection centres for injecting equipment, low threshold drug treatment services, remain operations outside the 'norm' and as 'special' services to those who are unworthy in the community.

This argument overlaps with ideas concerning reorientation of services and healthy public policy, but points to the consideration of these services as 'unusual' and 'undesirable' in comparison to physical structures and services deemed necessary to the prevention of other public health and social priorities.

For example, the necessity for open space for recreation and traffic-calming road structures are deemed acceptable and desirable by our community for the facilitation of healthy living and exercise and the prevention of road injuries, respectively. The community has accepted that these facilities and structures are necessary and valued to create supportive environments for public health priorities.

Yet, services demonstrated to reduce hepatitis C incidence, such as NSPs and the Medically Supervised Injecting Centre, are frequently the target of attempts to close these services, sometimes resulting in success. (Korner and Treloar, 2004) This is despite clear evidence of their efficacy in terms of public health and social outcomes. (Health Outcomes International, 2002) The survival of a supportive physical environment to reduce hepatitis C incidence should be put before political responses to community perceptions of difference and undesirability. This is important in maintaining the physical and social health of particular sections of, and thus by implication, the entire community.

Reorienting services

People with hepatitis C, as with many health conditions, often have complex needs. For example, the high rates of mental health comorbidity within the illicit drug use population are well documented, as is the paucity of services to address these complex needs. (Friedman, et al, 2003) In addition to drug use and mental health needs, a positive diagnosis for hepatitis C potentially creates a range of

additional needs in the fields of monitoring, treatment, social support and transmission prevention.

Few services are individually equipped to deal with this wide range of issues, and as such, a systemic change to the management of most health issues to develop better coordinated and linked inter-agency operation is needed. A partnership model in which organisations or services work together to support clients with diverse and complex needs in an institutionally supportive way would be ideal. Institutional support for better integration of services would include issues which have been outlined before and will come later – issues of non-discriminatory policies of service and employment; organisationally supported workforce development programs in anti-discrimination, and programs which aim to serve those most disadvantaged in our community (or at least not add to the broadening of social inequalities between groups).

One example of a successful interagency group in this sector is *HepLink*, a network of professionals working in the hepatitis C field. This group, with the secretariat based at the Hepatitis C Council of NSW, aims to share information, resources and support and has been successful in attracting members from across NSW who meet face-to-face, as well as participate in an email forum.

A further aspect of service orientation is the struggle to incorporate best available evidence into policy and practice. This has been an issue for health care for some decades. (Logan and Graham, 1998; Lomas, 1993) In terms of discrimination, organisations can contribute to best-practice models by acknowledging the impact of discrimination on individuals.

An example of this can be drawn from infection control practices within health settings. The *C-change* report documented cases of infection control as discrimination. There are numerous ways in which infection control may be enacted as discrimination. For example, research in the hepatitis C and HIV fields shows that, among other things, refusal of treatment, pressure to disclose status, being placed at the end of the surgery list and variability in individual practitioners' decisions to use of infection-control practices have been perceived by consumers to be acts of discrimination. (Hopwood and Treloar, 2004; Bermingham and Kippax, 1998) The impact of this on individuals can be significant. Greater institutional awareness and action on this count by reviewing and monitoring implementation of standard infection-control precautions could significantly reduce this source of hepatitis C-related discrimination.

In the past decade or more, there has been a growing awareness of and commitment to consumer participation in the development, delivery and evaluation of services. This is a key area in relation to making service providers aware of the impact of organisational policies and practices on the individuals who access services. Significant advances in this area have been made.

The Australian Injecting and Illicit Drug Users' League (AIVL), the peak body of Australian drug user organisations, has a well-developed charter for consumer involvement in services, and models this commitment through working with its member organisations. At the core of AIVL's position on consumer representation is the need to go beyond token appointment of one consumer representative on a committee to a well-resourced process of consultation with the community. In this way, AIVL emphasises that it remains the committee's responsibility to consult widely and effectively with consumer community: the consumer representative may assist them in developing an effective way to conduct that consultation process. (AIVL, 2003)

Strengthening community action

Health promotion is achieved through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities – their ownership and control of their own endeavours and destinies. (World Health Organization, 1986)

In Australia, a federal bipartisan political approach recognised this need to strengthen community action in the 1980s at a time when HIV/AIDS was starting to take hold in the gay communities, and before HIV was introduced in any significant way into the communities of people who inject illicit drugs.

The partnership established between the political process, HIV-affected communities and the health care and research sectors served Australia well in its widely acknowledged ability to address both HIV transmission and help reduce HIV-related discrimination. The same approach has served hepatitis C less well on account of a lack of stability of the affected communities and limited financial support their representative agencies are able to attract, a perceived lack of credibility of people who inject illicit drugs and prohibitionist policies regarding the main risk factor for hepatitis C infection. (Orr and Leeder, 1997; Puplick, 2003)

While appropriate structures in the form of publicly funded Hepatitis Councils and peer-based drug user agencies have been established in all states and territories, and funded national agencies such as the Australian Hepatitis Council and AIVL provide education and advocacy services at a national level, the effectiveness of their work in combating discrimination is limited given the lack of comprehensive political support for harm-reduction approaches that form the basis of hepatitis C prevention initiatives.

Community action is hindered too by a lack of strong political leadership at both federal and state levels, a paucity of research funding for assessing and establishing improved prevention approaches or for analysing the costs of the hepatitis C epidemic. Stigma of injecting drug use, coupled with support for prohibitionist policies make discrimination against all people with hepatitis C harder to address, and public support harder to win. (Puplick, 2003)

Effective community action is perhaps hindered most of all by having no high-profile public figures with hepatitis C willing to be associated with campaigns and programs, and by not having a cohesive 'community' of hepatitis C-affected people. Compared to HIV-affected communities, hepatitis C has no political constituency and those affected by it tend to have weaker social networks. (Orr and Leeder, 1997) While Hepatitis Councils and user groups can and do provide leadership, there are far fewer people among those affected by hepatitis C who have political and media skills comparable to those among HIV-affected communities (Puplick, 2003) and fewer still who can attract support and opportunities to develop these skills.

An example of such leadership is the National Hepatitis C Anti-Discrimination Project 2002-2003 carried out by the Australian Hepatitis Council on behalf of all state and territory Hepatitis Councils. This helped build the capacity of council staff and volunteers to work with clients who are discriminated against, and assist them to assert their rights in relation to anti-discrimination and privacy laws. (Australian Hepatitis Council, 2002)

Additional barriers of stigma and discrimination are faced by people with hepatitis C if they are from Indigenous Australian, youth, rural or remote, culturally and linguistically diverse or injecting drug using communities, or if they are in prison. Apart from young people, these populations are specifically identified in the National Hepatitis C Strategy as being priority populations. (Commonwealth Department of Health and Aged Care, 2000a)

It is important to note that while a range of commensurate activities and approaches need to be addressed simultaneously in order to address discrimination, an integral part of that response is the full involvement and empowerment of communities affected by infectious blood-borne viruses such as hepatitis C or HIV.

Building healthy public policy

Australia has a good track record in developing public policy that calls for health to be placed on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health. The first National Hepatitis C Strategy and the fourth National HIV/AIDS Strategy set clear direction for addressing both epidemics within the broader contexts of other population health initiatives that have a bearing on the health and well-being of people living with and affected by hepatitis C, or HIV/AIDS. (Commonwealth Department of Health and Aged Care, 2000a; Commonwealth Department of Health and Aged Care, 2000b)

Some states and territory governments have developed localised strategies to address the challenges of hepatitis C and HIV/AIDS transmission prevention, care, management, treatment and education.

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- Representative ministerial advisory frameworks and inter-governmental committees exist at the federal and state and territory levels to guide the implementation of such strategies and policies.
- Legislative frameworks are in place across Australia that outlaw discrimination against people with hepatitis C or HIV/AIDS, and complaints mechanisms exist to assist people to seek redress when they are discriminated against.
- The commitment to a whole-of-government approach, through Australia's acceptance of the 1986 *Ottawa Charter* and the 1997 *Jakarta Declaration on Leading Health Promotion into the 21st Century* should enable individuals and communities to exercise control over their own health.
- The importance of preventing HIV transmission in Australia has led to pragmatic legislative, policy and program responses designed to minimise harm. (Commonwealth Department of Health and Aged Care, 2000b)

In theory therefore, Australia's health public policy should be sufficient to ensure the impact of the HIV/AIDS and hepatitis C epidemics is minimal. In reality, the situation is very different.

Certainly in the case of the hepatitis C epidemic, a review of Australia's first National Hepatitis C Strategy found it achieved two important goals: it had established a good foundation for action and contributed to an increased awareness of hepatitis C as a serious public health problem. But the strategy had not succeeded in controlling the hepatitis C epidemic in Australia. (Commonwealth of Australia, 2003)

A number of serious constraints to the strategy's implementation were noted. Clearly these would additionally impede the ability of this major public policy to address hepatitis C-related discrimination. Chief amongst these were:

- a focus on risk factors and individual behaviour change in the absence of a comparable focus on risk contexts and settings (a broader health-promotion approach would increase the effectiveness of future strategies)
- a lack of resources for implementation of the strategy
- erosion of harm reduction through drug laws and drug policies, despite evidence and advocacy against this from affected and professional communities; and
- inadequate research and rudimentary surveillance

The review calls for, *inter alia*, a second hepatitis C strategy to be supported by appropriate legislative frameworks, including drug law reform and anti-discrimination measures, necessary because of the magnitude of the epidemic.

The crux of the matter, in terms of one aspect of public policy, is the growing recognition that criminalisation of injecting drug use has not been effective in controlling the hepatitis C epidemic. Rather, the review found, it has contributed

to increased transmission rates of hepatitis C among people who inject drugs. The review, commissioned by the Commonwealth government of Australia, considered that people who inject drugs have a right to the same standard of health care as all other citizens in the general community.

A 'public inquiries' approach to individual complaints within the confines of existing legislation is a strong means of addressing discrimination. The previously mentioned HIV/AIDS and hepatitis C enquiries have been significant in:

- documenting the nature and extent of discrimination
- examining the effectiveness of anti-discrimination law in providing redress, and
- making wide-ranging recommendations which aim to tackle discrimination

However, other mechanisms are required to facilitate greater access and efficacy of an individual complaints process to counter discrimination. Research into recent legislative and policy approaches to address systemic discrimination in the public sector in the UK and Canada found a number of positive trends. (Smyth and Falk, 2003)

In much the same way as employers have a general positive duty to ensure the protection of the health and safety of employees at work, so should there be a duty on the part of employers and service providers to promote equality, address past and present disadvantage and eliminate discrimination. The duty would be detailed by statutory requirements, guidelines and best-practice codes. This is a move away from sole reliance upon reactive, individual complaint-based models, one of the barriers to addressing discrimination.

In addition, trends in the UK and Canada indicate a move towards complaint handling models which provide complainants with direct access to tribunals in conjunction with options for alternative dispute resolution, and towards providing anti-discrimination boards or commissions with the capacity to act in tribunal cases on behalf of complainants or in the public interest.

Some have argued for the consideration of appropriate safeguards to support these initiatives, whether by way of a Bill of Rights or by other means, which ensure that Parliament enacts laws which promote equality and that the agents of government act in accordance with such principles. (Smyth and Falk, 2003)

Conclusion

Discrimination experienced by people affected by hepatitis C has significant impacts on most aspects of individuals' lives. These impacts are direct, such as personal reactions to specific events, and indirect, for example, withdrawal from treatment or prevention services or closure of services. Although some similarities exist, there is a vital and undeniably political difference between discrimination directed towards the HIV and hepatitis C 'communities' and the range of possible

options to counter such discrimination. The ongoing positioning of drug use as a criminal activity rather than as an issue of social and health policy facilitates hepatitis C-related discrimination to be perpetuated on legal, political and moral grounds.

While the principles contained within the Ottawa Charter have to be filtered through the constraints of prohibition, the public health, clinical and social aspects of hepatitis C will be left compromised and with inferior outcomes.

Given the entrenched nature of hepatitis C-related discrimination in many aspects of Australian society, we chose to explore the status quo and potential for change within the framework of the Ottawa Charter for Health Promotion. The five principles of the Ottawa Charter prompted us to consider the issue from individual, environmental, service delivery, community and public policy perspectives. Calls for action within each of the five areas of the Charter makes for a complex, yet realistic, multifaceted program of activities to counter hepatitis C-related discrimination in the Australian community.

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Notes

- 1 In some jurisdictions the term 'impairment' is used which is generally understood in similar terms to 'disability'.

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Discrimination and workers

by Anne Mijch

Many workers, but most particularly those in the health care sector, have been confronted with and responded to multiple challenges over the 20 years of emerging HIV and viral hepatitis epidemics in Australia. These include confronting the fear of previously unknown infectious diseases, responding to adverse and uncertain outcomes on an individual and community basis, addressing personal fears of contagion, and developing and integrating personal and workplace responses into the ethical and legal framework of non-judgemental, human rights-based societal responses and evidence-based scientific responses.

For individuals with HIV, hepatitis C (HCV) and, to a lesser degree, hepatitis B (HBV) infection, freedom from discrimination in the workplace, access to privacy and confidentiality of personal information and access to safe appropriate work environments has been an ongoing concern. Once again, this has been particularly important for those involved in health care settings, as well as in work settings where testing has been considered mandatory, such as in the military forces, prisons and the sex industry.

In the workplace, as in society in general, dealing with infectious agents associated with sexual transmission and injection drug use has always been compounded by judgemental stances to infected individuals and populations at risk. Discrimination is coloured by responses to sexual preference, injection drug behaviours, particularly in disadvantaged, racial and ethnic minority groups (which are increasingly over-represented amongst those with HIV and viral hepatitis).

In many workplaces the response to blood-borne viruses (BBV) has moved through the following stages:

1. Initial recognition of risk, often related to individual case descriptions or media reports with substantial community fear and often some misunderstanding of actual risks.
2. Calls for compulsory testing of population/group with quarantine, exclusion and legislative limitation of activities considered to enhance risk.
3. Review of quantum of risks and identification of modifiable risk factors with the development of epidemiological, community, policy and planning responses.
4. Application of harm-minimisation principles to the development of local policies and procedures.

5. Legislative response to balance human rights principles with community safety.
6. Community ownership of specific issues involved and of the evidence-based harm-minimisation response.

The following table describes the factors commonly considered in developing a comprehensive response to HIV, HCV and HBV in the workplace.

Factors considered in defining workplace response to blood-borne viruses (BBV)	
Evidence of transmission risk	Exposure to blood, body fluids
	Prevalence of BBV amongst workers
	Documented episodes of infection
Quantum of transmission risk	Relative to other work-associated risks
	Relative to community risk
Methods of risk reduction	Availability of and access to vaccination
	Environmental protection methodologies
	Availability of and access to personal protective measures
	Post-exposure procedures in place
Workplace safety for infected individuals	Safety from additional exposure risks
	Protections from personal discrimination and privacy safeguards
	Risk-reduction strategies available
	Opportunities and supports for return to work post illness
Workforce education and attitude	Level of understanding of HIV/HCV/HBV
	Attitudes to risk reduction and personal protection in general
	Attitudes to work-based risk reduction
	Understanding of discrimination
Legislative framework	Laws and guidelines applicable to specific workplace

The development of the legal response in Australia at the community level and as pertaining to specific community groups has been addressed elsewhere in this monograph. This chapter deals in particular with the response to HIV and viral hepatitis within the workplace, highlighting the principles that have come to underpin the development of rational and non-discriminatory responses.

Despite many successes, discrimination continues within the Australian community. This hampers access to prevention, treatment and care. As the epidemic changes in the Australian setting, workers and workplaces will be obliged to evolve responses to emerging issues. Some of these include re-entry to the work force of individuals responding to treatments, new challenges in marginalised minority populations and the issues raised by migration and refugees in the setting of international and neighbouring country epidemics, and access to evidence-based prevention and care in prisons and juvenile justice systems.

The legal response

Early in the HIV/AIDS epidemic in Australia, debate raged around appropriate legal responses. Some were protagonists of protecting the community from harm by enacting laws, such as a penalty for unprotected sexual intercourse by infected persons and offences of knowingly spreading HIV in some Australian states. Others argued that such an approach would only add to the stigmatisation of minority and alienated groups, and argued instead for other strategies, including effective media presentation of AIDS information to the general public, ready and cheap supply of condoms, and a new approach to injection drug use. Over the last two decades, Australian jurisdictions have introduced measures aimed at protecting the rights of people most at risk of infection and thereby encouraging sustained behaviour modification.

Workplace rights were established through discrimination legislation, particularly that which evolved in Commonwealth and almost all states in relation to disability. Federal and state-based anti-discrimination laws (particularly NSW) have come to prohibit discrimination against a person on the basis of their hepatitis C or HIV status, in specific areas of public life. The Anti-Discrimination Act and the *Disability Discrimination Act 1992* (Commonwealth) prohibit discrimination on the ground of disability in areas such as employment, education, accommodation and the provision of goods and services. Under both Acts, 'disability' is defined to include the presence in the body of organisms causing, or capable of causing, disease or illness. This includes both HIV and hepatitis. The Act also includes assumed, past and future disabilities – thus prohibiting discrimination on the assumption of HIV or hepatitis infection.

As an example, the NSW *Anti-Discrimination Act 1977* identifies the following grounds and circumstances where this applies.

The following types (or grounds) of discrimination are prohibited by the Act:

- Race
- Sex
- Marital status
- Homosexuality/lesbianism
- Intellectual impairment

- Physical impairment
- Compulsory retirement on the ground of age [is prohibited]
- Racial vilification [is unlawful]

But, they are only prohibited if they happen in one of the following areas:

- Employment
- State (but not private) education
- Obtaining goods and services
- Accommodation
- Registered clubs
- Access to places and vehicles (for race only)
- Access to places where liquor is sold (for sex only)

And they must not be subject to special or general exceptions under the Act.

Despite these legal frameworks, it is clear that, especially in relation to HCV, discrimination remains rife. The NSW Anti-discrimination Board enquiry into HCV discrimination identified substantial discrimination in the workplace, as well as in relation to access to health care provision. (Anti-Discrimination Board of NSW, 2001)

Major discrimination issues were identified for individuals who have or are suspected of having HCV, particularly those who:

- inject drugs,
- are imprisoned,
- work in health care,
- are involved in military service,
- work in the sex industry,
- work in the corrections service,
- belong to ethnic minority populations, or
- are indigenous Australians.

The Australian response in the following specific workplaces will be discussed in this chapter:

- health care settings
- sex industry
- correctional settings, and
- military forces

Health care settings

The recognition of blood-borne viruses – initially HBV, then HIV, and subsequently HCV – has had a substantial impact on the development of standards of infection control in health care settings. Guidelines based on requirements to identify specific infections in order to implement appropriate protective actions have been replaced by an understanding that all health care practices should be standardised to minimise transmission risks. A system of Standard Precautions was defined by

the National Health and Medical Research Council in 1996. (NHMRC and ANCA, 1996)

Standard precautions were introduced as standard operating procedures that apply to the care and treatment of all patients, regardless of their perceived infectious risk. These precautions include aseptic techniques, hand washing, use of personal protective equipment, appropriate reprocessing of instruments and equipment, and implementing environmental controls. Standard precautions should incorporate safe systems for dealing with sharp instruments, especially needles and syringes, handling blood (including dried blood), other body fluids, secretions and excretions (excluding sweat), especially in the setting of non-intact skin and mucous membranes.

Additional precautions were outlined for when standard precautions may not be sufficient to prevent the transmission of infectious agents, for example, tuberculosis, measles, Creutzfeldt-Jakob disease. Operating procedures were introduced to deal with the following, independently of the infectious status of the patient/s:

- handling of blood and body substances,
- personal protective practices (hand washing) and measures (appropriate use of gloves),
- needlestick and other blood or body fluid incidents involving either patients or health care workers including access to assessment and post-exposure prophylaxis, and
- an organisational protocol for managing, reporting and preventing this type of injury.

Universal access to hepatitis B vaccination, and staff education and training in regard to blood-borne virus prevention and management, became standard requirements across public and private facilities.

Despite the general introduction of these precautions, controversy raged in relation to some speciality areas – surgical sub-specialties and dentistry – and in relation to specific sections of the health care industry, such as mental health and intellectual disability services. The major areas of debate were around:

- The need for screening patients for BBVs prior to treatment: This was often thought to offer a degree of reassurance to those practitioners uncertain of their own risk, and those who incorrectly assumed that lower standards of practice would be safe and acceptable in the absence of a positive screen in an individual patient.
- The process of obtaining individual patient consent: In the setting of emerging requirements for pre- and post-test counselling this was seen by some as beyond the capability and responsibility of large sections of the health care industry. An emphasis on the difficulties obscured the real benefits of education and support opportunities.

- The obligations of health care providers in relation to patient behaviours which were often perceived by the community as different, illicit or unacceptable. This stood in contrast to their individual responsibility to respond in a non-discriminatory, evidence-based manner to the health care requirements of those infected with or affected by BBVs.

In dealing at multiple levels with the specific details of these debates, many organisations have developed guidelines and position statements supporting the human rights-based, evidence-supported stance of infection control and harm minimisation.

The introduction of vaccines (which in the case of hepatitis B can protect health care providers from chronic infection) and the introduction of treatments for hepatitis C and HIV have required a revisiting of the approach to risk reduction in health care settings. Treatments either allow some individuals to clear HCV or to reduce viral load and transmission risk, and improve patient outcome in HIV and reduce viral load and transmission risk.

The table at right identifies specific responses to working with and workers with BBVs in the health care setting.

The infected health care worker

The approach to health care workers (HCWs) who themselves are infected with blood-borne virus has been contentious in almost all jurisdictions. Once again the response was initially one of fear, exclusion and screening. In fact, one widely reported episode of patient-to-patient transmission in the context of poor infection-control practice has been influential on the unrelated issue of infected health care workers.

The response has generally been formulated in terms of types of likely activities by health care workers – specifying those thought to have particular potential for exposure to blood and body fluids of patients. These activities were designated as exposure-prone procedures (EPP).

Definitions of EPP varied from any activity involving sharp instruments potentially in contact with blood and body fluids to subsequent more specific definitions, for example:

A subset of ‘invasive procedures’ characterised by the potential for direct contact between the skin (usually finger or thumb) of the health care worker (HCW) and sharp surgical instruments, needles, or sharp tissues (spicules of bone or teeth) in body cavities or in poorly visualised or confined body sites (including the mouth). An exposure-prone procedure has been considered to be any situation where there is a potentially high risk of transmission of blood-borne disease from HCW to patient during medical or dental procedures.

Most often HCWs are seen to be professionally and ethically obliged to know their infectious status for HIV, HBV and HCV and to seek voluntary testing where appropriate.

Factors considered in defining workplace response to BBVs and health care workers in Australia		
Evidence of transmission risk	Exposure to blood, body fluids	Yes, patient to practitioner
	Prevalence of BBV amongst workers	HIV/HBV/HCV at community prevalence levels
	Documented episodes of infection	Yes, case reports of HIV, HCV and substantial HBV transmission
Quantum of transmission risk	Relative to other work associated risks	Needlestick injury from infected individual: HIV 1/300; HCV 1/30; HBV 1/3
	Relative to community risk	Increased
Methods of risk reduction	Availability of and access to vaccination	OHS standard practice Recommendation: universal HBV vaccine
	Environmental protection methodologies	Sharps prevention, needle-less systems
	Availability of and access to personal protective measures	OHS standard practice
	Post-exposure procedures in place	Widely available for HIV, HBV
Workplace safety for infected individuals	Safety from additional exposure risks	Special risks in immunocompromised individuals and contagious infections, e.g. tuberculosis
	Protection from personal discrimination and privacy safeguards	Recommendations in all jurisdictions
	Risk-reduction strategies available	Yes, avoidance of exposure-related work environments
	Opportunities and supports for return to work post illness	Variable
Workforce education and attitude	Level of understanding of HIV/HCV/HBV	Standard quality measure of workforce development
	Attitudes to risk reduction and personal protection in general	Generally excellent, provided privacy guaranteed
	Attitudes to work-based risk reduction	Variable
	Understanding of discrimination	Variable
Legislative framework	Laws and guidelines applicable to workplace	Legislation in all jurisdictions

OHS = occupational health and safety

The draft NHMRC infection control guidelines (2002) modified limitations of activity of infected HCWs to state the following:

- HCWs must not perform exposure-prone procedures if they are: HIV antibody positive; hepatitis B 'e' antigen (HBeAg) positive, and/or HBV DNA positive at high titres, hepatitis C virus antibody positive and HCV RNA positive (by polymerase chain reaction or similar test).
- Under current notification requirements, medical practitioners must notify the chief medical officer or state/territory health department of cases of HIV, HBV and HCV, either by name or code.
- A medical practitioner may also be legally obliged to bring to the attention of the appropriate registration board any registered professional who is unable to practise competently and/or poses a threat to public safety
- Similar infection control precautions, professional conduct codes, protection of privacy and confidentiality procedures apply to health care trainees as to qualified HCWs.
- Health care establishments should have comprehensive occupational health and safety procedures

Guidelines will need further modification in relation to BBV-infected health care workers to include assessment of risk and to take account of available treatments and the detection of markers of viraemia and transmission risk. Thus future guidelines could preclude HCWs performing EPPs if they are:

- HIV antibody positive and remain viraemic by the most sensitive assay available
- HBV infected (HBV surface antigen positive) and HBeAg positive, and/or HBV DNA positive at high titres; (the UK Department of Health suggested that greater than 1000 genome equivalents per mL represented a risk in relation to HBV DNA. It is likely that understanding of transmission risk will emerge in this area with new treatment availability)
- HCV antibody positive and HCV RNA positive (by polymerase chain reaction or similar test)

Thus the evolution of the response in the health care setting has followed developments in the understanding of epidemiology and the integration of newer biological factors, including direct measures of infectivity, and access to treatments for blood-borne viruses.

The sex industry

A current approach to work within this industry is presented in the light of factors as below.

Early in the history of HIV in Australia sections of the media, together with a number of health care workers, and at least one Parliamentary enquiry into prostitution in NSW in 1986, raised concerns that female sex workers would spread the

Factors considered in defining workplace response to BBVs and sex workers in Australia		
Evidence of transmission risk	Exposure to blood, body fluids	Potentially yes
	Prevalence of BBV amongst workers	HIV/HBV: rare HCV: moderate
	Documented episodes of infection	Nil
Quantum of transmission risk	Relative to other work-associated risks	Undefined
	Relative to community risk	Increased
Methods of risk reduction	Availability of and access to vaccination	Condom, lubricant; OHS standard practice Recommendation: universal HBV vaccine
	Environmental protection methodologies	Nil
	Availability of and access to personal protective measures	OHS standard practice
	Post-exposure procedures in place	Information and access to general NPEP
Workplace safety for infected individuals	Safety from additional exposure risks	More in brothels than street prostitution
	Protections from personal discrimination and privacy safeguards	Jurisdiction-dependent
	Risk-reduction strategies available	Process to access alternative financial and work options in some jurisdictions (HIV only)
	Opportunities and supports for return to work post-illness	Nil
Workforce education and attitude between jurisdictions	Level of understanding of HIV/HCV/HBV	Community and health service projects: varied
	Attitudes to risk reduction and personal protection in general	Excellent in legalised settings, less in street-based settings
	Attitudes to work-based risk reduction	Variable
	Understanding of discrimination	Variable
Legislative framework	Laws and guidelines applicable to workplace	Legislation in all jurisdictions

NPEP = non-occupational post-exposure prophylaxis

infection to the heterosexual community. In fact, calls were made for compulsory testing, registration and even quarantine during the 1980s.

Instead, individual organisations were established, funded and commenced effective education and outreach to sex workers. These organisations (including the Prostitutes Collective of Victoria, Scarlet Alliance and subsequently others) have emphasised safe sex within an occupational health framework and undertook education, training and service provision including needle and syringe exchange. The educative role of sex workers in relation to their clients has been an under-recognised opportunity in many jurisdictions.

In the 1990s, a number of episodes of 'investigative journalism' resulted in re-examination of quarantine, isolation and compulsory testing of sex workers. Current approaches are generally based on support to access treatment and care, financial security and alternative occupations. No evidence of sex worker-to-client transmission has been reported in Australia.

A confounding issue in the Australian approach to sex workers has been the approach to sex-on-premises venues. In these settings (where consenting adults meet, commonly consenting men who have sex with men), it was recognised that unprotected sexual activity posed a risk of HIV and HBV transmission. This resulted in calls for closure, screening of clientele, prosecution of proprietors and patrons. In many, but not all, jurisdictions and venues the prohibitive response has been replaced by safe-sex education, availability of prevention methods (especially condoms) and even access to treatment referral.

Responses to clubs, saunas and bars – whilst not directly involved in the sex industry – as work-related venues influences the ongoing controversy and contention in relation to appropriate standards, guidelines and policies in both settings.

Correctional settings

In Australia, as in many countries, prisons are recognised as environments where BBV-infected individuals are disproportionately congregated. Reported prevalence of HIV amongst male Australian prisoners at reception is 0.1%. HCV is extremely prevalent amongst both male and female prisoners. Although not routinely reported to Australian surveillance authorities, individual surveys suggest 70-80% of individual prisoners have evidence of HCV infection. HBV is also more frequent in prison populations.

The potential for transmission creates difficulties for both prisoners and prison staff, and has resulted in large variations in approach to this work environment in relation to HIV, HCV and HBV diagnosis, prevention, treatment and care. The underlying principles are tabulated as follows.

In mid-1990, a prison worker was attacked with a blood-filled syringe and infected with HIV. This resulted in initial calls for the quarantine of infected

Factors considered in defining workplace response to BBVs and correctional service workers and prisoners in Australia		
Evidence of transmission risk	Exposure to blood, body fluids	Potentially yes
	Prevalence of BBV amongst workers	HIV/HBV/HCV rare case reports
	Documented episodes of infection	One episode of HIV
Quantum of transmission risk	Relative to other work-associated risks	Low, unquantified
	Relative to community risk	Assumed increased, no quantification
Methods of risk reduction	Availability of and access to vaccination	Recommendation: universal HBV vaccine
	Environmental protection methodologies	Available personal protective procedures
	Availability of and access to personal protective measures	OHS standard practice
	Post-exposure procedures in place	Information and access to general NPEP
Workplace safety for infected individuals	Safety from additional exposure risks	Not defined
	Protections from personal discrimination and privacy safeguards	Jurisdiction-dependent
	Risk-reduction strategies available	Not specified
	Opportunities and supports for return to work post illness	Not identified
Workforce education and attitude	Level of understanding of HIV/HCV/HBV	Substantial workforce education, differs by jurisdiction and time period
	Attitudes to risk reduction and personal protection in general	OHS standard
	Attitudes to work-based risk reduction	Unknown
	Understanding of discrimination	Variable
Legislative framework	Laws and guidelines applicable to workplace	Legislation in all jurisdictions

prisoners. Subsequent experience has revealed low levels of HIV infection, but high HCV prevalence in custodial settings. Harm minimisation has been introduced into some prisons in the form of access to condoms and lubricants. But despite authoritative recommendations, access to needle and syringe programs,

substitution therapy, HBV vaccination, and antiviral treatment of HCV and HIV is inconsistently available across Australian jurisdictions.

Medico-legal responses suggest that recognition of evidence-based harm minimisation, and access to vaccination and appropriate care, support and treatment remains an urgent, but inconsistently implemented, requirement for custodial settings.

Military forces

Regulations require that Australian Defence Force (ADF) members must be 'free from any of the blood-borne viruses' to be determined 'medically fit for operational and non-operational duties'. These rules specify that 'ADF members who have a blood-borne disease and who, after all appropriate serological tests have been conducted, are diagnosed as being infectious with that disease are non-deployable'.

Members in this situation are to:

- receive mandatory counselling from their service medical officer on the health, personal and career implications of their diagnosis;
- have their medical employment classification reviewed to determine their fitness to continue serving in the ADF; and
- have their medical and dental records clearly marked 'NOT TO DONATE BLOOD OR OTHER TISSUE'.

It is the policy of the Australian military that applicants diagnosed with a blood-borne disease on enlistment testing are not to be enlisted or appointed.

In regard to serving personnel (including reserve personnel on active duty), serological testing is performed in the following situations:

- all blood donors at the time of donation;
- members who may have been exposed to risk of contracting a blood-borne disease;
- where there is a clinical indication for such testing;
- members identified through contact tracing;
- routinely at three months after members have returned from a specified operational deployment or exercise, or immediately on return if it is determined that the member has had a high-risk exposure to a blood-borne disease while on deployment;
- aircrew – annually (HIV only); and
- members proceeding overseas where such testing is an immigration entry requirement for the country being visited, or if testing is a compulsory requirement by a host country where the member is proceeding for training (members proceeding overseas on official visits or short-term attachments would not normally be tested).

The underlying principles in relation to military personnel are tabulated as follows.

Factors considered in defining workplace response to BBVs and military personnel in Australia		
Evidence of transmission risk	Exposure to blood, body fluids	No
	Prevalence of BBV amongst workers	Not different to general community
	Documented episodes of infection	No
Quantum of transmission risk	Relative to other work-associated risks	Low, unquantified
	Relative to community risk	No evidence of increased risk
Methods of risk reduction	Availability of and access to vaccination	Recommendation: universal HBV vaccine
	Environmental protection methodologies	Available personal protective procedures
	Availability of and access to personal protective measures	OHS standard practice
	Post-exposure procedures in place	Information access to general NPEP
Workplace safety for infected individuals	Safety from additional exposure risks	Not defined
	Protections from personal discrimination and privacy safeguards	Nil
	Risk-reduction strategies available	Not specified
	Opportunities and supports for return to work post illness	Not identified
Workforce education and attitude	Level of understanding of HIV/HCV/HBV	Low level in general
	Attitudes to risk reduction and personal protection in general	OHS standard
	Attitudes to work-based risk reduction	Unknown
	Understanding of discrimination	Variable
Legislative framework	Laws and guidelines applicable to workplace	Specific regulations

In general, regulations specify military force exclusions for individuals with blood-borne viruses. Justification is said to be based on concern about possible risk of disease, a position not reviewed in the era of therapy and which is based on opinion rather than definitive evidence of adverse performance. In relation to

issues of transfusion risk, the regulations require standard donor deferral and screening which has effectively protected against transfusion-related blood-borne viral transmission.

In relation to non-overseas deployed personnel, screening has not been required except in specific circumstances. Again the dichotomy is based on guidelines rather than evidence of differential risk of transmission, disease or ill health.

Conclusion

In relation to the response to BBV in the work force, the six essential components of Australia's response have reduced, but not eliminated discrimination. These principles are worth re-stating in conclusion:

1. developing partnerships and involving affected workers,
2. access and equity to work based on best-quality evidence
3. harm reduction as approach to prevention of transmission and minimising disease in the workplace,
4. health promotion for individuals infected,
5. research and surveillance to identify real local and workplace situations, and
6. linked strategies and legislative responses to underpin the workplaces and the community response.

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Public health, criminal law and HIV/AIDS

by Helen Watchirs

HIV transmission can involve confronting human dramas and scenarios related to sex, drugs, blood and disease. Most criminal law cases that have come to the attention of authorities concern men exposing women to HIV infection, despite the fact that the epidemic in Australia is disproportionately concentrated among men who have sex with men. This may be due to the gay community's attempts to internalise the norm of individual responsibility for a safer sex culture, and a lesser expectation of a partner's disclosure of HIV status in casual relationships, compared to heterosexual relationships. These exceptional cases are often salaciously reported by the media and induce moral panic – they reflect the inadequacy of legal solutions to the complex problems of promoting responsible intimate behaviour.

Although the cases and principles explored in this article concern HIV transmission, they could equally apply to other communicable diseases, such as hepatitis C – although the main mode of infection with the latter is through needle sharing rather than sex, and thus involves different stigmatised sub-populations.

In 2002, a HIV-positive married man was convicted in Perth of grievous bodily harm for transmitting the virus to an eighteen-year-old young woman he had met through an internet chat room. He had explicitly denied that he was infected. (Agence France-Presse, 2002) The 35-year-old man was diagnosed with HIV in 1990, but had not infected his wife, nor their three children.

In the 1990s, there were a number of cases in Melbourne where convictions for reckless endangerment through exposure to HIV transmission were overturned, with enormous media resentment. The cases usually involved the scenario of a man exposing his girlfriends without warning them of the risk of HIV transmission, but one concerned an HIV-positive psychiatric detainee who had sex with his cellmate in the City Watchhouse after telling him that he was HIV-negative.¹

In 1987, Sydney newspapers covered the story of a HIV-positive sex worker. In 1989, 'Sharleen' appeared on the *60 Minutes* television program to explain why she continued to sell sex (which was generally safe, but some clients insisted on unsafe sex for which they paid more). She was later involuntarily detained under public health laws. (Perkins, 1991: 157-158)

This chapter considers proposals for law reform in Australia that would enable balanced approaches to regulating recalcitrant behaviour through proportionate interventions. Recommendations for law reform have already been made by a series of government, expert and community bodies in Australia, including a recent paper for the Australian National Council on AIDS, Hepatitis C and Related Disease (ANCAHRD). But progress at state and territory levels has been slow. This chapter charts the current state of public health and criminal laws in states and territories.

A health and human rights approach

International human rights obligations merit implementation at local levels in their own right, but public health is an additional justification in the context of the HIV epidemic. Taking a human rights approach involves integrating the international norms and standards that have been developed by the United Nations human rights regime into the design, implementation and evaluation of HIV/AIDS policies and programs.

The local effectiveness of such an approach should be assessed against its ability to make a real difference in terms of preventing transmission, enabling those infected and affected by HIV to cope better with the consequences of infection, and mobilising the involvement of individuals and civil society in the response. Punitive laws have little impact on the spread of the virus in the majority of cases because transmission often occurs when there is lack of knowledge of one's own HIV status, especially in developing countries, where over 90% of the epidemic is concentrated.

Human rights and public health principles are usually complementary, in theory, but the area of disease transmission and exposure creates a potential tension that requires adequate resolution in law, policy and practice. Public health is vitally connected to human rights protections at the individual and community levels. Traditional public health interventions prior to the HIV epidemic have often undermined human rights through paternalism, overstepping the express but limited public health exception that is contained in several human rights treaties by exercising coercive legislative powers such as compulsory testing, detention and treatment. A human rights approach requires a fair balance to be achieved between the interests of people who are, may be, or are not infected with diseases such as HIV/AIDS.

The health and human rights movement principally founded by the late Jonathan Mann, but continued by other leading figures and communities around the globe, recognises that human rights concepts such as human dignity provide a persuasive paradigm for identifying and understanding the essential conditions in which people can exercise their right to health. (Mann, 1999)

A human rights approach recognises social vulnerability, not just in public health terms of individual choice and risk behaviour. Disempowered and stigmatised populations – such as gay men, injecting drug users and women (under threat of domestic violence, for example) – are constrained by their social conditions and not fully free to choose rational actions. (Rothenberg and Paskey, 1995; Zierler, 2000) An over-inclusive criminalisation approach treats people living with HIV/AIDS as potential criminals, and there is a risk that sanctions will be disproportionately targeted by law enforcers at vulnerable groups, such as the homeless.

To enable human rights objectives to be implemented requires some practical bridging mechanism between general treaty requirements and domestic legal systems. The *International Guidelines on HIV/AIDS and Human Rights* adopted by an International Consultation in 1996, and partially updated in 2002, provide guidance on how general human rights obligations apply at national levels in the specific area of HIV/AIDS. In relation to criminal and public health laws it recommends:

Criminal and/or public health legislation should not include specific offences against the deliberate and intentional transmission of HIV, but rather should apply general criminal offences to these exceptional cases. Such application should ensure that the elements of foreseeability, intent, causality and consent are clearly and legally established to support a guilty verdict and/or harsher penalties. (Office of the High Commissioner for Human Rights and UNAIDS, 1996)

Assessing whether countries comply with the benchmarks in the guidelines is the subject of an audit methodology developed by the author, and the results of its general application in Australia have informed the legal analysis of state and territory laws in this paper. (Watchirs, 2002a: 77; Watchirs, 2002b: 716) The process of drafting the guidelines involved several Australian law reformers who were acutely aware of the issues, influenced by the seminal work of a national body, which is discussed below.²

The Australian policy context

Public health and criminal law offences regarding disease transmission or exposure vary among Australian jurisdictions and require amendment to make them more consistent, effective and compliant with human rights obligations. Many current provisions contrast with the general tenor of HIV/AIDS reform in Australia and the principles espoused in the various national strategies, which has been one of voluntarism, and contributed to a relatively high level of HIV testing and status self-awareness.

The *Fourth National HIV/AIDS Strategy* replicates the partnership approach of earlier strategies and emphasises the need for a supportive and enabling environment, including legal protection in terms of discrimination and human rights.

It explicitly commits to further developing ‘a social and legal environment that protects the rights of people living with HIV/AIDS and encourages people whose behaviours place them at risk of contracting the virus, to participate at all levels of the response to the epidemic’. (Commonwealth Department of Health and Aged Care, 2000: paragraph 2.2)

A central guiding principle is that the legal framework should be ‘rational, non-coercive and responsive’ and that it reiterates the anti-exceptionalism of earlier strategies – ‘laws specifically created to deal with HIV/AIDS require particular justification’. (Commonwealth Department of Health and Aged Care, 2000: paragraph 3.1.3)

This principle is not met in most Australian jurisdictions, which specifically criminalise HIV transmission rather than rely on general provisions. A table at the end of this chapter sets out the specific and general public health and criminal law provisions relating to disease transmission and/or exposure. Only the ACT and Northern Territory do not have public health transmission offences applicable to HIV, and several jurisdictions have HIV-specific criminal offences, such as Victoria and NSW.

It has been recognised that coercive measures focusing on general population outcomes can risk driving individuals most in need of prevention, care and support services underground, and thereby out of reach. (Dwyer, 1993: 167) Responsive regulation has increasingly been applied to minimise HIV transmission through public health laws, involving a pyramid with a range of escalating powers, with cooperative strategies used at the base and more coercive strategies further up the hierarchy. (Braithwaite and Ayres, 1992) For example, public health civil commitment processes should be preceded by counselling, limitations on work and other activities, with detention as a last resort.

Graded interventions restricting living circumstances have generally worked well in states and territories (such as public health orders), but are best implemented in direct relation to measures preventing transmission (such as counselling, supervising, directing that only safe sex can be undertaken, or detaining people). These interventions usually take place within a broad legislative framework with detailed policy guidance – for example in 1990 both the Victorian and NSW Health Departments issued management guidelines, which have since been drafted in most jurisdictions. (Victorian Health Department, 1990; NSW Health Department, 1990; Queensland Health, 2000)

Public health powers applicable to HIV/AIDS require legislative controls similar to other public law powers in comparable areas (for example, mental health), including due process protections, such as providing for fair hearing of cases, and rights of review and appeal against orders restricting liberty.

Old public health laws have required amendment because they are not coherent in protecting fundamental values such as due process, certainty, consistency

and predictability, and also on practical grounds of ineffectiveness. Some laws automatically applied measures to HIV which were designed for casually transmitted diseases, such as quarantine procedures, banning infected people from working in certain industries (pharmaceutical industries and cheese factories, for example) and requiring them to notify bus drivers of their condition.

I would argue that HIV and disease-specific criminal offences should be repealed, and instead a new generic offence enacted – endangerment of life and health by intentional or reckless conduct (including, but not limited to, disease transmission) with defences of voluntary acceptance of risk of death or serious harm. In addition, public health legislation needs general statements of principles to highlight the human rights and public health objectives that the law is seeking to balance. Clear statements of intent assist decision-makers in individual cases.

A criminal law approach is only warranted in exceptional cases of deliberate transmission, as it is a blunt tool that is generally not successful in changing intimate, complex and private behaviour. (Watchirs, 1992: 3-5) Punitive approaches rely more on matters such as deterrence, retribution and incapacitation (removal of the offender from the community) than rehabilitation. (Braithwaite, 2001)

Irresponsible behaviour in which harm is intentionally or recklessly inflicted upon others should not be treated exceptionally, just because HIV/AIDS is involved. (Burris, 1994: 251; Bayer, 1991a: 1500) The ability to transmit HIV is a power that can be exercised responsibly or abused, and needs to be held in check by accountability measures. However, punishment under the law should be reserved for the most serious cases of culpable behaviour as a last resort.

The most persuasive argument against having traditional communicable disease interventions (such as compulsory testing, treatment and isolation) in strategies responding to the epidemic is that HIV (and hepatitis C) is not casually transmissible. However, the main modes of transmission, unsafe sex and needle sharing are not casual behaviours. Restrictive measures may be justified if they are not counter-productive.

Criminal offences applicable to HIV are more limited in scope than public health powers, with several jurisdictions only having general or specific offences related to reckless endangerment of harm or injury, or causing disease. Over-inclusive laws that allocate blame can undermine education campaigns encouraging all parties engaging in risk activities to be responsible for adopting preventive measures, rather than making unreliable assumptions about someone's HIV status. (Closen, 1991: 921)

Some of these criminal offences were introduced in several jurisdictions in the early 1990s in response to cases where assailants used syringes filled with blood, alleging that they were HIV-infected – so-called 'needle bandits'.³ Regulating public violent behaviour such as this is not simple, but it is less complex than private consensual behaviour, such as sex and needle sharing. (Bayer, 1991b)

Criminalising the making of false blood donor declarations does not have the same policy implications as the private behaviours already discussed. The use of contaminated blood violates the right to health of others and there is no countervailing or legitimate public interest in allowing the donation of infected blood. No jurisdiction has yet established a legislative protocol to ensure that criminal prosecutions of disease transmission cases require the approval of the Director of Public Prosecutions or Attorney-General, to ensure that health authorities are consulted before charges are laid.

Expert law reform recommendations

There has not been a shortage of recommendations in the area of HIV/AIDS, public health and criminal law in Australia and internationally, but there has been a lack of comprehensively implemented law reform.

The Legal Working Party of the Intergovernmental Committee on AIDS (LWP, IGCA) convened a national law reform process involving state, territory and Commonwealth health and law agencies from 1990 to 1992. (Watchirs, 1998) It warned that there was a danger of stigmatising already alienated groups by creating special HIV offences rather than general offences.

Unfortunately, reactive legislative responses have accompanied media hysteria from high-profile exceptional cases, such as ‘Sharleen’ described above. Such responses in the early days of the epidemic were opposed, on the basis that they could result in what Justice Michael Kirby of the Australian High Court dubbed ‘HUL – highly useless laws’. (Kirby, 1988)

Instead, the LWP recommended the enactment of a general ‘knowing exposure’ offence, with a full defence where protective measures are taken, and a lesser penalty where transmission has nevertheless occurred (despite these precautions). Charges should only be brought by police after approval by public health authorities, so that the risk of transmission can be scientifically evaluated, and cases individually assessed as to the appropriate steps to be taken in a series of graded interventions using public health legislative powers.

The LWP recommended that such powers to place restrictions on the living and working conditions of persons who put others at unreasonable risk of infection should be used only in exceptional cases, and subject to due process protections, including supervision by courts. Approximately half of the LWP’s recommendations in a number of areas were implemented in the period immediately surrounding the process, but the public health area was generally more successful (with the exception of some jurisdictions who still have not reviewed or amended their legislation) than the criminal law area.

Provisions in public health legislation mainly relate to knowing or reckless exposure or infection, with most jurisdictions specifying the behaviour concerned (i.e. sex), but one jurisdiction (Tasmania) includes needle-sharing. Several juris-

dictions provide defences where the other person has been informed of the risk of transmission and voluntarily agrees to accept it. No jurisdiction specifically regulates mother to child transmission. Some jurisdictions have negative offences for failing to take reasonable precautions, which are not specified. Most jurisdictions have more indirect provisions by giving public health officials or courts coercive powers to make public health orders, directions or notices and by providing penalties for failure to comply. Laws range greatly in terms of the extent of power and how they are structured in terms of the criteria required to be satisfied, as well as due process protections, such as review and appeal rights. Only one jurisdiction, Tasmania, has a separate legislative scheme for dealing with HIV/AIDS, but it largely overlaps with general public health laws covering notifiable diseases.

ANCAHRD

Other bodies taking up the national law reform gauntlet include ANCAHRD and the National Public Health Partnership. An ANCAHRD paper released in 2002, which is within the life of the *Fourth National HIV/AIDS Strategy*, included the four following guiding principles, the first three of which have not yet been fully implemented. (Watchirs, 2002c)

PRINCIPLE 1: Existing state and territory laws should be amended to include an offence of intentionally or recklessly placing others at risk of harm (including, but not limited to disease transmission). Disease and HIV-specific provisions should be repealed.

PRINCIPLE 2: Defences of voluntary acceptance of risk of death or serious harm should be available for general intentional or reckless endangerment offences involving disease transmission.

PRINCIPLE 3: A legislative protocol should be established for prosecution of endangerment cases involving disease transmission including requirement to gain approval of the Attorney-General or Director of Public Prosecutions, in consultation with public health authorities, before charges are laid.

PRINCIPLE 4: Public health powers should be retained subject to legislative controls including: graded interventions; transparent process providing for hearing of cases before liberty is restricted; and providing for appeal against orders restricting liberty.

The arguments supporting these principles are sound. Criminal responsibility for behaviour is premised on the accused's capacity to make voluntary choices and understand the significance of the acts in question. The offences recommended include deliberate and reckless⁴, rather than merely negligent behaviour, as it would be over-inclusive to punish mere ignorance of HIV status. A generic offence does not unfairly discriminate between irresponsible behaviour in different contexts, as it includes endangerment through HIV and other disease transmission or exposure by any means (for example, 'needle bandits'), as well as

through other equivalent dangers such as weapons, whether or not it involves a disease. Also, the offence recommended covers exposure as well as actual HIV transmission, because the risk behaviour is the principal target of the law, and consequences as determined by luck or fate should not be a determining factor – intervention should not be delayed until actual infection.

Defences to these offences are necessary to enable partners the freedom to choose whether to voluntarily engage in activities with informed consent – any paternalism blocking this process would impede communication between both parties and with health professionals. There are also human rights such as privacy that protect expression through private and mutually consensual sexual acts, even though social and medical burdens may ensue with the further spread of disease. Lack of consent is often an element of existing public health offences, and could easily be incorporated into a new offence, but use of precautionary measures may not be necessary as an explicit defence, since it goes to the heart of the issue of whether the endangerment offence is made out. Exempting safer-sex behaviour in this way should act as a positive encouragement, rather than deterrent for prevention activities.

Several jurisdictions have administrative, rather than legislative, protocols requiring prosecution of cases involving disease transmission to gain approval of the Attorney-General or Director of Public Prosecutions, who would consult with public health authorities, before charges are laid. Such protocols are necessary to act as a check on unwarranted responses, and instead offer flexible support for underlying problems (drug use necessitating sex work to finance addiction, for example), and proper information to all the parties involved in the case.

The ANCAHRD principles adopt the Victorian public health legislative model as best practice (but improved in the area of review rights) – it subjects authorities to administrative law accountability mechanisms, such as general principles of interpretation to guide decision-makers, structured discretions, natural justice and due process protections (including notification of full merits review and appeal rights, giving reasons for decisions, maximum duration of orders, regular review of orders, and regular medical examination of persons detained). The principles do not recommend removing offences that impose penalties for non-compliance with preventive public health orders, as these provisions can be effective regulatory mechanisms to improve enforcement.

Model Criminal Code Officers Committee

The ANCAHRD principles address issues considered by the Model Criminal Code Officers Committee (MCCOC) – also a comprehensive state, territory and Commonwealth law reform body that attempted to achieve national uniformity – but in the general area of criminal responsibility. (Criminal Law Officers Committee of the Standing Committee of Attorneys-General, 1992)

MCCOC recommended the enactment of a general endangerment offence and new principles that replace the old twin criminal law elements of acts causing harm and a guilty intent, with equivalent physical (conduct, circumstance or result) and fault (intention, knowledge, recklessness and negligence) elements. In 1996, the committee suggested the inclusion of a reckless endangerment offence that was specific to disease transmission, contrary to the IWP's recommendations, to overcome some Victorian cases which had held that unprotected sexual intercourse could not constitute endangerment since the risk of HIV transmission in a single encounter was remote, and not an 'appreciable' risk of danger.⁵ There has since been a successful conviction in Perth for HIV transmission under a general criminal law provision, namely grievous bodily harm.⁶

The committee's model code in respect of non-fatal offences against the person published in 1998 contains two general, rather than disease-specific, reckless endangerment offences (life and serious harm, respectively). (MCCOC, 1998) The code also has general offences relating to intentionally causing and negligently causing harm and serious harm, which explicitly cover infection with a disease. There is no defence of voluntary assumption of risk, and the general defence of consent to harm does not appear to be applicable to disease transmission in acts such as sex or needle sharing, because it requires the act in question to have a social benefit, such as in sporting or medical practices. The interpretation section (5.1.24) accompanying the endangerment offences attempts to clarify their application to conduct involving disease transmission:

- it includes exposing a person to the risk of catching a disease that may give rise to a danger of death or serious harm;
- it includes conduct that is ordinarily capable of creating a real, and not merely a theoretical, danger of death or serious harm;
- it is irrespective of the statistical or arithmetical calculation of the degree of risk of death or serious harm; and
- it is not necessary to prove that a person was actually placed in danger of death or serious harm by the conduct.

The code has been adopted for Commonwealth offences, but states have been slow to comprehensively amend their laws, except in relation to computer offences and generally in the ACT, which is implementing the code in stages.⁷

Responses

In 1999, the AIDS Council of NSW and People Living with HIV/AIDS NSW made a submission to a review of the *Public Health Act 1991* that generally supported the MCCOC approach to a general reckless endangerment offence, and recommended the repeal of disease-specific public health and criminal offences. (ACON and PLWHA Inc., 1999) In relation to the four MCCOC interpretation provisions set out above, it only supported three of them and rejected the third criteria as

unnecessary (which attempted to overcome the Victorian case law on appreciable risk of danger described above).

It also recommended that two specific defences be provided for – voluntary assumption of risk, and use of reasonable measures (including precautions such as safer sex). Consistent with the earlier LWP report and the later ANCAHRD paper, it recommended the development of a protocol between police, the Director of Public Prosecutions and the health department to ensure that an integrated and proportional approach is taken in cases involving placing another person at risk of a sexually transmissible infection.

The National Public Health Partnership's 2002 draft *Discussion Paper on Notifiable Diseases* recommended that powers to make public health orders be counter-balanced with individual human rights, by enacting guiding principles of rights and responsibilities to guide administration. (2002) Its general recommendations were consistent with the earlier LWP and ANCAHRD specific recommendations, such as establishing review rights and using a flexible case-management approach, forming a hierarchy of least to most restrictive measures (ranging from counselling, restriction of behaviour and activities, supervision, treatment – to reduce infectivity, and be complete to prevent resistance to certain drugs – to detention or isolation).

International approaches

These Australian policy approaches are consistent with overseas studies. The Canadian report on *Criminal Law and HIV/AIDS* concluded that public policy aimed at criminalising HIV transmission or endangerment did little to stem the spread of HIV and diverted attention and resources from effective measures, such as access to education, means of protection, voluntary testing, counselling, support and treatment, and addressing issues of individual and societal vulnerability. (Joint Project of Legal and Ethical Issues of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society, 1997)

There have been several convictions for HIV exposure or transmission without using HIV specific offences in Canada. In *R v Cuerrier* the Supreme Court held that fraudulent non-disclosure of HIV status negated consent to sex and founded a conviction for assault.⁸ In *R v Thornton* the court found that knowingly donating infected blood was a public or common nuisance, which is a generic common law offence. (Bronitt, 1994b)

UNAIDS engaged the Canadian HIV/AIDS Legal Network to draft a policy options paper in 2002, which noted that there were also practical difficulties in proving offences beyond a reasonable doubt, including the accused's knowledge of his or her HIV status and the means of transmission, the content of communications between the parties without the presence of witnesses (such as whether deceit was involved) and whether the accused was the actual source of infection (for example, by genetic fingerprinting of the virus). (Elliot, 2002)

The South African Law Commission and AIDS Law Project (ALP) similarly rejected the need for HIV specific offences – the ALP argued that it would reinforce gender inequity by perpetuating patterns of subordination that make women disproportionately vulnerable to infection. (South African Law Commission, 2001; AIDS Law Project, 1999)

Conclusion

It is important for the Commonwealth to provide leadership on the issue of state and territory public health and criminal laws by promoting implementation of the ANCAHRD 2002 principles outlined above. The *Fourth National Strategy on HIV/AIDS* contained principles that are so broad that states and territories could complacently claim that they are already in place, although in substance much law reform work remains to be done to implement recommendations made by expert advisory bodies – as outlined above.

A consistent approach is required in Australian jurisdictions to the issue of criminalising disease transmission or exposure, as currently the law varies according to where the alleged risk-taking act occurred. The aim of law reform in the HIV/AIDS context is to shape the actual content of provisions in order to attempt to make them effective in terms of preventing and reducing infection, while also being sensitive to human rights concerns.

Providing an appropriate legal framework for dealing with the problem of deliberate and irresponsible behaviour should provide a supportive environment for people infected and affected by the epidemic. Laws inappropriately criminalising certain behaviour can act as an impediment. Appropriate laws can be used constructively to communicate societal values and guide behaviour through providing public health and human rights protections, and remedies for abuse to individuals. The ultimate goal should be to empower people to protect themselves through behaviour change, by accessing education and information, and openly discussing and negotiating the use of protection measures in the intimate and sensitive areas of sex and drug use.

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Notes

- 1 *Mutemeri v Cheeseman*, unreported Supreme Court decision of April 29, 1998. R v D, unreported Supreme Court decision of May 1, 1996. R v B, unreported Supreme Court decision of July 3, 1995.
- 2 These included Justice Michael Kirby of the High Court who chaired the consultation (and the consultations preceding and following the 1996 one), and the author as the consultant responsible for drafting.

- 3 The amendments were the *Crimes (Injuries) Amendments Act 1990 (NSW)*, the *Crimes (HIV) Act 1993 (Victoria)* and the *Criminal Law Amendment Act (No. 2) 1992 (WA)*.
- 4 Recklessness means foreseeing the results of conduct, but nevertheless taking the risk of bringing it about. (Bronitt, 1994a)
- 5 *R v B* (July 3, 1995) and *R v D* (May 1, 1996), reported in *Criminal Law Journal*, Vol. 21, 1997, p. 40. In those cases the accused was acquitted of endangerment charges because of medical evidence that the risk was 1 in 200 or less.
- 6 *R v Ronald Houghton*, unreported decision of Justice Muller, District Court of Western Australia, October 3, 2002. The defendant was sentenced to seven years' imprisonment upon conviction by a jury. There is also a New Zealand case involving consensual sex where HIV was transmitted, resulting in a conviction of grievous bodily harm: *R v Mwai*, reported in *New Zealand Law Review*, Vol. 3, 1995, P. 149. (Court of Appeal)
- 7 *The Criminal Code 2002, ACT* adopts many parts of Chapters 2 and 4 of the model code – general principles of criminal responsibility and computer and property damage offences. The *Criminal Code (Theft, Fraud, Bribery and Related Offences) Amendment Bill 2003* will implement much of Chapter 3 of the model code. See also serious computer offences under sections 308F-G, *Crimes Act 1900, NSW*.
- 8 Canadian Criminal Cases (Third series), Vol. 127, 1998, p. 1. (Supreme Court of Canada)

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Appendix: Table of Australian jurisdictions

Jurisdiction	Public health provisions	Criminal law provisions
NSW	s.13: offence – sex with sexually transmissible medical condition s.11: offence – failure to take precautions in public	s.36: malicious cause/attempt grievous bodily disease
Victoria	s.120: offence – knowing/reckless infection s.121(10): offence – failure to comply with order	s.22: reckless endangerment s.19A: intentional infection with very serious disease (HIV)
Queensland	s.48: offence – knowing or reckless exposure or infection s.36 (6): offence – failure to remain in isolation	s.317 (b): intentional transmission of serious disease s.339 unlawful assault occasioning bodily harm
SA	s.37: offence – failure to take prevention measures	s.29(1)-(3): reckless endangerment of life, grievous bodily harm or harm
WA	s.264(1): offence for wilful exposure of infectious disease in public place	s.294(8): act resulting in serious disease s.297: grievous bodily harm
Tasmania	HIV/AIDS: s.20(2): offence – awareness and knowing or reckless exposure s.20(1): obligation to take reasonable precautions Notifiable diseases: s.51: offence for knowing or reckless exposure and obligation to take reasonable precautions	s.170: intentionally causing actual bodily harm s.172: unlawfully causing grievous bodily harm
ACT	s.118(4): offence – failure to comply with public health order	s.23: intentional/reckless infliction of actual bodily harm
NT	s.38(2): offence – failure to comply with Chief Health Officer's order	s.154: causing serious actual or potential danger to lives, health or safety

Pregnancy and HIV: a human rights perspective

by Kirsty Machon

The issue of HIV-positive women and pregnancy has always been emotive, and frequently complicated both ethically and morally. Prior to the advent of effective antiretroviral treatment (ARV), women with HIV were routinely advised that they should terminate pregnancies rather than take the risk that the child would be born HIV positive. HIV-positive women who hoped to have a child by choice were routinely told that it was out of the question. Estimates of the likelihood of a child being born HIV positive to an HIV-infected mother vary considerably, and depend on a range of factors, such as the mother's viral load and CD4 count during pregnancy. However, studies have shown that in the absence of treatment for the mother and other interventions to reduce the risk of transmission, up to 30% of children may contract HIV during pregnancy, birth or through breastfeeding. (McDonald, et al, 2001: 449)

Advances in treatment mean it is quite clinically appropriate for many HIV-positive women to have children, but such advances have brought with them their own complex questions. Two phrases which can sum up an overall philosophy for managing pregnancy in HIV-positive women within a framework based on human rights which accounts for the rights of both mother and child are 'considered planning' and 'shared care'. The philosophy and practice of 'shared care' stresses the importance of a close liaison between each of the medical practitioners responsible for managing aspects of a pregnancy – including a general practitioner, obstetrics specialist, or midwife – so that each is provided with a total picture of the health of both the mother and her child.

Background

Reported rates of vertical HIV transmission without ARV vary. However, overwhelming evidence testifies that appropriate HIV antiretroviral treatment and optimal clinical management can reduce this figure to less than 1%.

The now very real possibility of having an HIV-negative child is important for many women who have been HIV positive for some years, and were previously told (often at the same time as their diagnosis) that they could expect a drastically foreshortened life, and would never be able to have children.

Epidemiological figures attest to the dramatic and rapid change in transmission. In 1992 to 1993, 23 babies in Australia were born to HIV-positive women, and seven of these babies were born HIV positive. Between 1998 and 2002, a total of

133 babies were born to HIV-positive mothers. Of these women, 112 were aware of their HIV-positive status before the baby was born. Not one of these 112 women gave birth to an HIV-positive baby. A smaller group of 20 women did not become aware of their HIV status until a later stage: at, or after, the birth of the child. Eleven of the babies born to this group of women were HIV positive. (NCHECR, 2003: 47)

These figures provide strong evidence that with ample opportunity for the appropriate planning, clinical management and support of a pregnancy, most HIV-positive women will have successful pregnancies and HIV-negative babies.

Mechanisms of transmission

There are primarily three ways in which HIV is transmitted between mothers and children. These are:

- transplacental (during pregnancy)
- intra-partum (via contact with blood or body fluids during the birth)
- through breastfeeding.

A high viral load and a low CD4 count are two of the critical factors that can increase risk and incidence of transmission. In general, good management of HIV in pregnancy aims at each one of these potential areas of transmission, and will include:

- reducing the mother's viral load through use of ARV as appropriate;
- appropriate interventions at the time of delivery, such as treatment of the child post-partum with ARVs, particularly if the mother has not taken anti-retroviral treatments;
- exploring the possibility of other modes of delivery (such as a Caesarean section), although evidence for this is less certain, and Caesarean is not recommended for all positive women; and
- alternatives to breastfeeding.

Yet this is far from the full picture of what is likely to be required to minimise risk of mother-to-child transmission. Managing pregnancy in HIV-positive women can be extremely complicated, presenting legal, ethical and clinical challenges from the point of conception through the early months of a child's life (and longer, if that child is born HIV positive).

It is also important to remember that 'good clinical management' needs to be approached with the health of the mother in mind as much as that of the child, and that 'health' in this context will mean considerably more than just viral load tests, CD4 cell counts or mechanically and strictly applied clinical antiretroviral therapy guidelines. Pregnancy can be physically and emotionally stressful for any woman. The added anxiety of HIV infection presents some difficult issues, particularly for those women who may receive their HIV diagnosis during their pregnancy.

Becoming pregnant

For many HIV-positive women of childbearing age, a healthy and successful pregnancy may involve a planning process which begins much earlier than the conception itself. Now that having a child is a viable option for these women, many doctors factor this possibility into their clinical treatment of women of childbearing age.

In some cases, and especially where women have indicated that they are considering having children at some stage, appropriate early management may extend to choosing HIV treatment combinations for women which spare the drugs most likely to be useful during pregnancy. In this case, if a woman develops resistance to her treatments, she will more likely remain sensitive to a range of drugs which can be used most effectively in pregnancy. Similarly, if a woman is planning or considering pregnancy, it will be important that she is counselled against the use of those treatments, such as efavirenz, which are known to be teratogenic.

Another important factor for many HIV-positive women will be the question of how to become pregnant safely, and particularly, without putting an HIV-negative partner at risk of infection.

These options need to be carefully discussed with the woman, and ideally, her partner, as there are various ethical, clinical and emotional issues which need to be taken into account.

Fertility testing

HIV may cause problems with fertility in some women. This may be complicated by issues such as symptomatic episodes of some sexually transmissible infections. A discussion about fertility, and if necessary, any clinical tests, should be offered to some women as part of the pregnancy planning process. Women who may have HIV-related fertility problems or who are unable to conceive may also need counselling or support to assist with this diagnosis.

Other testing

Other tests which are likely to be important in assisting women to make an appropriate decision will be a viral load test and CD4 count, tests for any other sexually transmissible infections, and other clinically relevant tests, such as hepatitis B or C antibody testing.

Insemination

Many women with HIV-negative partners or husbands choose to inseminate themselves with their partner's own semen, or donor sperm, using mechanical methods. This option is usually safe for both parties, in that it does not require unprotected sex. Women choosing this method should be counselled about

timing the insemination to the period of her menstrual cycle when she is most likely to fall pregnant. However, using donated sperm, or mechanical insemination, may also be emotionally unsatisfying for some couples.

In addition, women seeking donor sperm through clinics may be faced with varying practices and confusing messages, as there is no nationally consistent approach to the issue of HIV-positive parenting, and some sperm clinics are likely to be unwilling to provide sperm to HIV-positive women.

In vitro fertilisation

HIV itself, or some treatments, may interfere with hormonal cycles, reducing fertility. A Victorian woman in this situation sought access to in vitro fertilisation (IVF) in a case which went before the courts. The ruling was that HIV-positive women seeking access to fertility services should not necessarily be excluded. Rather, the court found that all applications from HIV-positive women should be considered on a case-by-case basis, and a range of factors will be taken into consideration.

This means IVF may be an option for some positive women with fertility problems (related or unrelated to HIV or treatments). However, IVF is an expensive, invasive and time-intensive procedure, and women should be counselled to rule out the possibility of simpler alternatives like self-insemination first.

There is an increasing amount of clinical experience with HIV-positive men who want to have children. IVF, using ‘washed’ sperm, or a new technique in which an individual sperm is treated for HIV and implanted directly into a single egg harvested from the mother, are two techniques which may be used. However, access to these approaches is limited and expensive in Australia, and will not be an option for all couples.

Unprotected sexual intercourse

Some women with HIV opt to become pregnant through unprotected sex with their partner. ‘Natural’ conception is emotionally satisfying and important to some women and couples, although it raises an obvious set of complications about the very real risk of transmission to an HIV-negative partner. A range of risk-reduction measures are used by people with HIV who have unprotected sex, but the risk is not negligible, and women need to be clearly counselled and aware of the risks associated with this option, as well as any information which may help the couple ensure that a decision to have unprotected sex is made on an informed basis.

For a woman considering this option, it may be especially important to be tested for viral load, CD4 count and any other sexually transmissible infections, to ensure that she is fertile, and to time any act of unprotected sex to the part of her menstrual cycle where she is most likely to fall pregnant. Ideally, discussion and, if relevant, testing, should include the woman’s partner.

Should a woman choose to conceive by unprotected sex with a partner not aware of her HIV-positive serostatus, this would raise a set of potential legal issues for a clinician who was aware of her intention. In all Australian states and territories, public health legislation exists in relation to people with HIV and other infectious diseases who do not disclose their diagnosis to their sexual partners before having unprotected sex, with a range of sanctions and redress. However, doctors are also ethically bound to protect the confidentiality of their patients. It would be important for any clinician faced with this dilemma to familiarise themselves with their legal obligations under public health legislation, as a recent case in NSW has shown.

Pregnancy in advanced HIV disease

One other important ethical consideration is the health of the mother herself, including the prognosis of disease progression. This is a sensitive and complex topic. In the first instance, it is an important clinical consideration, since pregnancy can pose a serious clinical risk for women with advanced HIV infection. Beyond this, though, clear ethical dilemmas are raised when an HIV-positive woman wishes to have a child at a late or advanced stage of HIV infection – particularly where there is the clear possibility she may become seriously ill, or even die, within the foreseeable future.

There are serious implications for a baby born HIV negative, should his mother become incapacitated by illness, or die when the child is very young. The most immediate and important consideration is establishing who would care for the child in the event of the death or illness of the mother – and to discuss what this may mean for the baby's long-term emotional and physical wellbeing.

For women with advanced illness who are considering pregnancy, this is very important, and does not always have an easy answer.

Treatment during pregnancy

Many HIV agencies and health organisations around the world have developed guidelines for the use of antiretroviral treatments during pregnancy. The purpose of this chapter is not to outline the clinical evidence in favour of or against particular agents or combinations, but to provide an outline of some of the broader issues raised when thinking about antiretroviral use in pregnancy.

It is first worth noting that attitudes to antiretroviral treatment may sometimes differ between women and men. Some women may be less likely to be confident about treatments, and may have more anxiety about side effects. The *HIV Futures* reports into the lives of HIV-positive Australians have consistently found that women report a lower level of use of antiretroviral therapies, although the most recent, *HIV Futures III*, did suggest that this gap was beginning to close. (McDonald, et al, 2003: vi)

There are valid reasons to be cautious about antiretroviral therapy in pregnancy, but for some women this anxiety may take extreme or even apparently unreasonable forms. This underscores the need for accessible, frank and balanced treatments education for all HIV-positive women.

Regardless of the choices they make about treatment or reproduction, all HIV-positive women have the right to make decisions about their health with access to all the necessary information, and without emotional or legal coercion (unless what they do is illegal).

The law may be a potent form of coercion, but so too are some of the emotive appeals to women's fears which form the basis of a lot of much misinformation about the risks and benefits of HIV treatments. This is an issue that may also need to be addressed by counselling, and a broader community-based educational program, including peer education, that helps demystify antiretroviral therapy.

Overwhelmingly, women in Australia choose to have antiretroviral therapy during pregnancy. The question of what treatments to take, however, can be a daunting and confusing one, hampered by a lack of readily available and accessible information which clearly outlines what is known and not known about individual drug treatments in pregnancy, and in particular, their potential effects on unborn children.

This situation is beginning to change, with more resources becoming available, and much more clinical experience of and published data about antiretrovirals used in pregnancy.

However, it is important that women have the opportunity to talk through this information in a non-judgemental environment, particularly as many women may quite reasonably refuse to interpret 'no information' as providing positive evidence that the treatment will therefore do no harm.

Antiretrovirals during pregnancy

Obviously, pregnancy does not and should not exclude the use of optimal ARVs. Reduction of maternal viral load to below 1000 copies per millilitre of blood appears to have an independent effect on rates of perinatal transmission. However, there are some considerations of safety and timing in relation to antiretroviral use in pregnancy. In general:

- women who are already taking antiretroviral treatments, and whose viral load remains low and CD4 count stable, would be advised to continue with this combination, unless the combination contains drugs known to be deleterious or harmful to the unborn child;
- in antiretroviral-naïve women, initiation of treatment can be delayed for the first trimester of the pregnancy (10–12 weeks) to avoid exposing the foetus to any potential teratogenic effects during the period where it may be most vulnerable;

- women diagnosed during the second or third trimester of pregnancy, particularly those with viral loads of over 1000 copies per millilitre or low CD4 cell counts should be counselled about the role of treatment in reducing perinatal transmission; and
- whether the mother is taking antiretroviral treatments or not, it is the accepted standard of clinical care to treat the mother during the birth (to minimise viral load), and the child post-partum, with one of several possible regimens of HIV treatment, most often including AZT.

Around the world, clinical trials have shown that short-term interventions during this period, and during the first weeks of a baby's life, can dramatically reduce infection rates in settings where it is unusual for a mother to have been treated during pregnancy.

Women who choose not to treat

In countries like Australia, with clear standards of care for all people with HIV, a confronting set of issues arises when women choose not to take antiretroviral therapy during pregnancy. Although overall attitudes to pregnancy in HIV-positive women have improved concomitant with treatment and improved knowledge, there may nonetheless be some real tensions between the rights of the mother, and the rights of her unborn or newly-born child. This ethical tension may emerge at its most extreme in those challenging cases where women do not wish to be treated with antiretroviral therapy, and also indicate they do not wish to have their baby treated post-partum with short-course antiretroviral therapy.

Some clinicians take the view that when there is a perceived conflict, the rights of unborn children must prevail over those of the mother. This may even extend to the suggestion, which arises from time to time in sectors of the clinical community, that women should be legally obliged to take antiretroviral treatments from the second trimester of pregnancy.

Other clinicians, however, maintain that during pregnancy, a woman retains a clear and unarguable jurisdiction over her own body, and therefore has the right to decide for herself whether she does or does not take antiviral treatment. In addition, treatment decisions may also need to be made with specific reference to the health and circumstances of the mother.

The latter is not always an easy position to take. It is possible to accept this view, but still feel strongly that it is in the best interests of women to be treated for HIV infection, especially if guidelines would ordinarily indicate treatment is appropriate, and because it may help prevent the transmission of HIV during pregnancy. Many clinicians are very clear: the bottom line is that it would be totally unacceptable and unethical to force an adult person — by legal or other means of persuasion or punishment — into taking HIV treatments. This is a view broadly supported by many people with HIV/AIDS, and national and state-based advocacy

groups, and would be absolutely in keeping with the commitment to informed free choice which underpins HIV advocacy.

What happens, though, after a child is born? There is a view in most sections of the community that a child has rights of his or her own, which are not subsumed within the rights of the parents. It follows from this that there is a legal duty of care owed by health professionals to a child whose mother is HIV positive, and this includes giving antiretroviral treatment where appropriate.

There is no legislation which can compel an HIV-positive woman to take antiretroviral therapy. Given the significant questions about the ongoing safety, clinical viability and tolerability of currently available antiretrovirals, there are no good public health, clinical or moral cases for such legislation. It would follow from this that there are no clear grounds to argue for any kind of 'mandatory' treatment interventions during pregnancy.

However, legal questions can and do arise in relation to the treatment of the child.

Post-partum treatment and the law

All state and territory supreme courts have inherent jurisdiction by which they are able to declare a child or minor a ward of the state, and intervene if it is believed a child is at risk of harm. A court order may be obtained by a state agency (for example, the Department of Community Services [DOCS] in NSW), or anyone who can demonstrate a significant interest in the child's welfare (such as a parent, grandparent, relevant health professional, or other family member).

In NSW, health care workers must report any situation where they believe a child is at risk of harm from abuse or neglect to DOCS. 'Risk of harm' refers to the likelihood a child or young person may suffer physical, psychological or emotional harm as a result of what is done or is not done by an adult responsible for their care. Under the NSW *Children and Young Persons (Care and Protection) Act 1998*, it is mandatory for health workers to report suspected risk of harm if they deliver health care partly or wholly to children. Obviously, this has legal implications for paediatric physicians.

Once a report is made to DOCS, this will be investigated. The Director-General of DOCS gives final advice on whether or not there is a sufficient evidence of risk of harm to intervene.

The Act also allows that a health care worker may make a pre-natal report (i.e. a report before a child is born), if they have reasonable grounds to suspect that child would be at risk of harm after his or her birth. Harm specifically includes any situation where parents or caregivers have not arranged and are unable or unwilling to arrange for the child or young person to receive necessary medical care.

Currently, Australia has national standard of care guidelines for people with HIV, which spell out what is considered standard of care, or best clinical practice,

in this area. Usually, any legal claim that a child may be at risk would be assessed against these guidelines, with the capacity for the courts to seek any additional expertise as they wish.

The most recent Australian guidelines, and more recent US guidelines, identify as the minimum standard of care for the children of HIV-positive mothers as anti-retroviral treatment post-partum, utilising AZT syrup for six weeks following birth.

This is in accordance with the Paediatric AIDS Clinical Trial Group (PACTG) Protocol 076. (HIV/AIDS Clinical Trials and Treatments Advisory Committee of the Australian National Council on AIDS and Related Diseases, 1999; Panel on Clinical Practices for Treatment of HIV Infection convened by the Department of Health and Human Services, 2003) PACTG 076 showed that AZT used during pregnancy, intra-partum, and critically, administered to the child in the first six weeks of life, reduced the risk of perinatal transmission by 66%. (Sperling, et al, 1996)

However, there are a number of caveats. Treatments guidelines are regularly reviewed, and they remain emphatically just that: guidelines. Guidelines also exist for the treatment of HIV in adults, and provide useful parameters for thinking about treatment decisions, but they are rarely used in clinical practice as literal 'how-to' manuals with universal applicability.

HIV treatment information changes all the time. Clinical factors such as viral load, CD4 count, attitudes to treatment, treatment history, side effects and the extent to which certain combinations suit individual lives are just some of the factors which influence a person's choice of treatment. Many people choose clinical combinations that are markedly different from the guidelines, and continue to do well.

So what happens if a woman who is not taking antiviral treatments during pregnancy chooses not to have her child treated after birth, and what implications does this have for the responsibility of all clinicians with a role in the management of HIV-positive women in pregnancy?

One answer is bluntly legal. If a state-based community services department formed the view that not treating a child constituted an unacceptable risk, they would be able to take the matter to court. Indeed, any one of a number of different people could apply to the court for a treatment order, in the absence of parental consent to treat the child: this might include relevant health professionals, grandparents or other family members. Witnesses might include parents and clinicians.

If the court were persuaded there was a real risk, they could order the child to be treated. The court would have the power to remove the child from its mother's care during the period of treatment. However, the removal of children is usually considered a last resort, and the legislation in NSW requires that a number of other options be exhausted first.

The complexities of how this can unfold are obvious from one case in an Australian state, where after legal action, child protection authorities arrived to remove a newborn baby from her HIV-positive mother (who was not on treatments), because the mother had indicated she did not wish her baby to be treated with antiretroviral therapy including AZT.

In this instance, the baby did eventually receive antiretroviral treatment, but community-based HIV workers who had been involved in this emotional case raised serious concerns about deficiencies in the processes and procedures followed by clinicians and others involved. In particular, it seems the mother was never informed that serious legal consequences could arise from her decision not to have her baby treated with antiretrovirals.

The implications

Although legal proceedings may bring about an apparently effective outcome (in that a court order may be obtained to treat the child or the mother may consent under this pressure), it is hardly best practice when a woman comes to this decision only under threat of severe and perhaps extremely distressing legal recrimination.

One of the most striking things about the above case is the apparent silence, until very late in the woman's pregnancy, about this issue.

In relation to women taking ARVs during pregnancy, the US guidelines are unequivocal: 'Discussion of treatment options should be non-coercive and final decision regarding the use of antiretroviral drugs is the responsibility of the woman ... A decision to refuse treatment with [AZT] or other drugs should not result in punitive action or denial of care.' (Public Health Service Task Force, 2003)

This view is overwhelmingly shared by the National Association of People Living with HIV/AIDS in Australia and its members. Any move to make treatment with antiretrovirals legally binding for anyone, including women in pregnancy, would contravene the Declaration of the Rights of People with HIV and AIDS. (NAPWA, 1994)

It is likely that some women may choose not to consent to treatment for their child. It remains critical that, if this is so, the woman understands the legal implications of her decision, and is clearly advised on how to best access appropriate legal advice or representation.

On this basis, community-based HIV groups have called for the development of national counselling guidelines, which cover all aspects of pregnancy management, ensure that women are well-informed about HIV and its implications, encourage referral and shared care arrangements between clinicians, and most importantly, ensure that women are informed about the legal implications of any treatment decision they may make regarding their baby.

It's obviously better for all concerned if decisions around treatment for both mother and child are reached clearly and respectfully. Medical and legal authority might be a weighty stick to wield and undoubtedly has the power to 'get results'. However, this does not necessarily equal an ideal public health outcome, and it is inappropriate for people to be compelled to make such personal, traumatic and difficult decisions through threats of legal intervention, or appeals to the authority of medical knowledge. Comprehensive counselling guidelines may protect the rights of everyone involved, including institutions and individual clinicians, and help minimise the need for the law to weigh in on what is often such a private, emotional and harrowing decision-making process.

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Australia's immigration response to HIV/AIDS

by Les Szaraz

Introduction

The purpose of this chapter is to examine some of the factors that have influenced the formulation of Australia's immigration policy in response to HIV/AIDS and the manner in which it is currently administered by the Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) [hereafter 'the Department'].

This examination will involve consideration of the following questions: Is anti-HIV sentiment a feature of Australia's immigration policy? Are HIV-positive applicants treated differently under the policy? If so, in what way and what are the implications and flow-on effects? How does Australia's immigration policy compare to that of other countries? And, lastly, given the prevailing political climate is there any room to agitate for a change to current policy?

It is worth noting that a specific response to hepatitis C has not emerged. However, the health requirement (as described below) applies equally to hepatitis C. Testing is not routinely required, but may be requested where there are clinical indications or a history warranting investigation.

Australia's immigration response to HIV/AIDS has been situated within a broader policy objective of limiting the potential financial burden that accompanies migrants and asylum seekers who may have complex and costly health care and community support needs. However, HIV/AIDS has been singled out as warranting special attention by requiring mandatory testing for those seeking permanent residence. This has arguably perpetuated a widely held misconception that having HIV will automatically result in refusal.

In order to appreciate how HIV/AIDS affects an application for temporary entry or permanent residence, it is essential to discuss the health requirement and the circumstances in which it may be waived.¹

Thereafter it will be possible to critique how HIV/AIDS fares under the policy rubric of protecting the Australian community from public health and safety risks, containing public expenditure on health care and community services, and safeguarding the access of Australian citizens and permanent residents to health care and community services that are in short supply. (DIMIA, 2003: Criteria 4005-4007)

Brief history

In 1989, Australia introduced mandatory screening for HIV for all permanent resident applicants aged 15 years and over. While the justification for the decision centred on economic arguments, it was also probably influenced by political debate in the 1980s that linked the spread of HIV to same-sex migration. (Hart, 2002: 18-20)

In 1985, the Human Rights Commission's review of the *Migration Act 1958* stated that permitting same-sex migration was likely to increase the threat of AIDS. (Hart, 2002: 18) Amidst the prejudice and fear surrounding the new and emerging HIV epidemic in the mid- to late 1980s, Australia adopted a policy of mandatory screening. However, questions remained as to the shape and form it would take.

The health requirement

Australia has a formally 'non-discriminatory' immigration policy. (DIMIA, 2002a) In accordance with this, applicants for both temporary and permanent entry must be assessed against the health requirement regardless of their country of origin, ethnicity, gender, colour or religion.²

The only exception to this is on-shore asylum seekers because their claims for protection as refugees³ are determined independently of their health status.⁴ Failure to meet the stringent health requirement will result in a refusal of a visa to travel to or remain in Australia except where there is provision to waive the health requirement. This provision is known as the 'health waiver' and will be discussed in detail below.

The health requirement requires that the applicant:⁵

- (a) is free from tuberculosis; and
- (b) is free from a disease or condition that is a threat to public health in Australia or a danger to the Australian community; and
- (c) is not a person who has a disease or condition to which the following subparagraphs apply:
 - (i) the disease or condition is such that a person who has it would be likely to:
 - (A) require health care or community services; or
 - (B) meet the medical criteria for the provision of a community service; during the applicant's proposed stay in Australia;
 - (ii) provision of any health care or community services relating to the disease or condition would be likely to:
 - (A) result in a significant cost to the Australian community in the areas of health care and community services; or

- (B) prejudice the access of an Australian citizen or permanent resident to health care or community services;
regardless of whether the health care or community services will be used in connection with the applicant; and
- (d) if the applicant is a person from whom the Medical Officer of the Commonwealth (MOC) has requested a signed undertaking to present himself or herself to a health authority in the state or territory of intended residence in Australia for a follow-up medical assessment, the applicant has provided such an undertaking.⁵

It is important to note the following regarding the health requirement:

- Tuberculosis (TB) is currently the only disease resulting in an automatic preclusion for a visa because it has been recognised by the World Health Organization as an epidemic and global emergency. Unlike the United States for example, Australia does not regard HIV/AIDS as a public health risk. Thus applicants found to be HIV positive are assessed on the same basis as those with any other pre-existing disease or condition.
- The term 'disease or condition' is intentionally broad and encompasses physical or mental illness, physical and intellectual disabilities, diseases such as HIV/AIDS and hepatitis and conditions such as obesity.
- The term 'community service' is very wide. It includes home and community care services, any special training or education needs and the provision of an Australian social security benefit, allowance or pension.⁶
- It only has to be 'likely' that the disease or condition will require health care or community services. This is known as the 'objective person access test'. That is, if ordinarily a person with the same or similar disease or condition would access health care and community services during the same time period as the applicant's proposed stay, then the applicant will fail the health requirement.
- The term 'significant cost' is defined by policy as being the 50% above the average per capita health care and community services cost for Australians over a five-year period. Currently this is between \$16,000 and \$20,000.
- An applicant would be 'likely' to prejudice the access of an Australian citizen or permanent resident if they require the use of resources in short supply for which there is a high demand. For example, transplantation, radiotherapy for the treatment of malignancy, haemodialysis for end-stage renal failure, blood or blood products on a recurring basis, nursing home placements and residential care for people with disabilities. (DIMIA, 2003: Criteria 4005-4007) HIV/AIDS health services are not in short supply in Australia and thus prejudice is rarely an issue.

- It does not matter if the applicant with the disease or condition is able to independently meet all the costs flowing from their disease or condition, has health insurance, or is to be cared for by family or friends, because the applicant is assessed against the health requirement regardless of whether they will actually access any health care or community support services.⁷

How the health requirement is assessed

In order to determine whether an applicant satisfies the health requirement, the Department is normally required to seek the opinion of the Medical Officer of the Commonwealth.⁸ The Department is then bound to accept the opinion of the MOC for the purpose of deciding whether the applicant satisfies the health requirement.⁹ In forming their opinion, the MOC may require the applicant to do any one or all of the following:

- complete the health declaration on the visa application form,
- obtain a medical certificate from their doctor,
- have a medical examination,
- have a chest x-ray,
- have an HIV, hepatitis B or other specific test required by the MOC.

Whether this will be necessary depends largely on the type of visa. However, it is always possible for the MOC to request additional information and/or tests for any visa. So, for example, if an applicant declares previous drug rehabilitation or intravenous drug use then they may be required to have an HIV and/or hepatitis test. (DIMIA, 2003: Criteria 4005-4007, Section 10.2)

Temporary entry

All applicants for temporary visas are generally required to satisfy the health requirement.¹⁰ Most will not be required to undergo any medical examinations or HIV screening. Their health declaration on the visa application form is usually accepted as evidence that they meet the health requirement.

However, other factors will determine which, if any, medical examinations or tests are required. These include the proposed length of stay in Australia, the incidence of TB in their home country or any other country visited for more than three months in the last five years, their intended activity in Australia, and their medical history.¹¹

For example, an applicant for a temporary student visa will usually be required to have a chest x-ray as they will be involved in classroom tuition with other students.

Interestingly, a 'pilot program' is currently in operation whereby all off-shore temporary student visa applicants aged 15 years or older from sub-Saharan Africa,¹² seeking a stay of 12 months or more, are required to undergo HIV

screening as part of their medical examination. (DIMIA, 2003: Criteria 4005-4007, Section 39) If found to be HIV positive, they would be unable to satisfy the health requirement.

It is worth noting that while HIV screening is not part of the temporary visa application process, it is indeed possible for an applicant to be refused a temporary visa if they declare that they have, or are found to have, HIV. This would depend on the MOC's opinion of the likely needs of the applicant during their proposed stay in Australia. But, generally, refusal of temporary visas based on HIV/AIDS is not commonplace.

Permanent residence

All applicants for permanent visas, except on-shore protection visa applicants,¹³ are required to satisfy the health requirement. Failure will result in visa refusal unless there is provision to waive the health requirement. All applicants are required to undergo:

- a medical examination,
- a chest x-ray if 11 years or older, or if appropriate on clinical grounds,
- HIV screening if 15 years or older, or if clinical indications or history give rise to the possibility of infection, or if applicant has been adopted, or if applicant has had a blood transfusion,
- hepatitis B screening if pregnant, or if the applicant is being adopted, or if there are clinical indications that they may be infected,
- any other screening considered appropriate on clinical grounds. (DIMIA, 2003: Criteria 4005-4007, Section 69)

The health requirement for permanent residence is assessed, with very few exceptions, on a 'one fails, all fail' basis. (DIMIA, 2003: Criteria 4005-4007, Section 68) The applicant and all members of their family unit, whether or not they intend to migrate to Australia, must meet the health requirement unless it would be unreasonable to require the non-applicant to be assessed against the health requirement. For example, it would be unreasonable to require this of an institutionalised member of the family unit who is unlikely to ever be discharged.

If an applicant or member of the applicant's family unit is found to be HIV positive, this in itself does not result in automatic rejection. However, they will almost invariably fail the 'objective person access test' and the 'significant cost' test in the health requirement, because it is generally accepted that a person with HIV/AIDS will access health care at least once every three months and that their health care and community service needs will be well in excess of \$16,000 over a five-year period. For example, the MOC has estimated that antiretroviral treatment alone costs on average \$12,000 a year.

Practically speaking, the only way in which an applicant who fails the health requirement can be granted permanent residence is if the health waiver is

available for the class of visa that they are applying for. The health waiver is available for the following classes of visa:¹⁴

- spouse/*de facto* spouse¹⁵
- prospective marriage¹⁶
- interdependency (which includes same-sex partners)¹⁷
- child¹⁸ and dependent child¹⁹
- adoption²⁰
- former resident (but only if served in the Australian Defence Force for at least three months)²¹
- close ties²²
- off-shore 'refugee' and special humanitarian²³
- witness protection²⁴
- business owner/investor²⁵

The health waiver

The health waiver allows the Department²⁶ to waive the health requirement if:²⁷

- (a) the applicant satisfies all other criteria of the grant of the visa applied for; and
- (b) the Minister is satisfied that the granting of the visa would be unlikely to result in:
 - (i) undue cost to the Australian community; or
 - (ii) undue prejudice to the access to health care or community services of an Australian citizen or permanent resident.

It is important to note the following about the health waiver:

- It is not available unless all other criteria for the visa are satisfied.
- It does not apply to (a) and (b) of the health requirement – i.e. if an applicant has a disease or condition that may be a threat to public health in Australia or a danger to the community, then the health waiver is not available.
- The health waiver test relates to whether granting the visa will result in 'undue' (unwarranted, unjustified and excessive) cost to the Australian community. There is thus a distinction between undue cost to the Australian community in the health waiver and significant cost to the Australian community in areas of health care and community services in the health requirement. This arguably allows consideration of the positive contribution that the applicant may bring to the Australian community in other ways, such as workforce participation and perhaps providing care to others (such as their HIV-positive partner, for example).
- As is the case with the health requirement, HIV/AIDS health services are not in short supply in Australia and thus undue prejudice is rarely an issue.

- The health waiver provision does not require the MOC to express an opinion that must be accepted by the decision-maker although this facet of the law is widely misunderstood by both departmental decision-makers and Migration Review Tribunal (MRT) members.²⁸

How the health waiver works

In practice, the lifetime cost estimated by the MOC for the health care for a person who tests positive to HIV is around \$240,000, with only occasional and small variations. The law only requires the MOC to make an estimate of cost over a lifetime, and does not require it to give any rationale to support this. It has not been the practice of the MOC to do so. It is also clear from the fact that estimates vary so little that the figure is a standardised one.

The MOC's estimate must be taken as correct only for the determination of the health requirement and not for the determination of the health waiver. The applicant will therefore approach their treating doctor and specialist to give a comparative estimate to that provided by the MOC.

Estimates from treating doctors and specialists vary considerably. For some people, costs will be high – ongoing treatment with antiretrovirals, serious treatment side effects, or an HIV-related illness. At the other end of the spectrum, there will be those who fall into the category of slow-progressors, who may not require treatment for their HIV disease in the foreseeable future. The difficulty of dealing with HIV/AIDS arises in practice.

When compared to the estimates put forward by treating doctors, the MOC's estimate is consistently too high. The standardised cost is only approached by that of a treating doctor where the prognosis for an individual is poor and significant medical intervention is required. Although there is no explanation for the MOC estimates, it seems clear that it is based on figures determined before 1996 – when antiretroviral therapy emerged.

In terms of significant cost, this poses a problem for those in whom the virus seems not to be progressing, or at least is progressing at an undetectable level. There are therefore some people who will fail the health requirement and have to apply for a health waiver, when the cost of their treatment will, in fact, be under the significant cost threshold.

Theoretically this need not be a problem as the decision-maker is not bound by the MOC when looking at undue cost and the health waiver. All a decision-maker needs do is understand that the MOC cost is standardised and not individualised, and therefore accept the individual estimate (based on good evidence), waive the health requirement and issue the visa. Unfortunately, in practice this has not been the case, and the obligation to accept the best evidence and not be bound by the MOC is either little understood or ignored by the decision-maker. This is evident in all of the decisions of the Department, and to a large extent in the decisions of the MRT.

This therefore gives rise to the situation where a person who on an individual level should pass the health requirement, instead fails the significant cost test, applies for a health waiver, and additionally is not granted the waiver by the Department on the erroneous basis that the estimate of the MOC must be taken as correct. The applicant must then seek a review of the decision by the MRT. If the health waiver was applied by the Department, as it should be, and the visa granted, then the process should not take more than about six months, including providing the additional medical evidence.

Instead, the process takes approximately three years, because the applicant must appeal the decision to the MRT. The initial application spends approximately 18 months at the Department. Here a further problem arises as the result of departmental policy which states that any application for a health waiver where the significant cost is estimated as being over \$200,000 will require assessment by the Ministerial Health Unit in Canberra. As the standardised cost for HIV estimated by the MOC is always over \$200,000, this requirement applies to all HIV/AIDS applications.

Because of the erroneous belief that the decision-maker is bound by the MOC estimate, almost all HIV health waivers are rejected by the Department and require an appeal to the MRT. So the applications spend another 18 months at the MRT. Even then, the visa is not guaranteed, as it is not widely appreciated even at MRT level that the decision-maker should privilege the individualised evidence.

An applicant is entitled to get the cost reviewed by a Review Medical Officer of the Commonwealth (RMOC), providing the RMOC with the applicant's treating doctors' reports. There is a considerable fee for a review, and it seems in practice that it is rare that the RMOC estimates costs at a different figure to that of the MOC.

When looking at whether the cost is 'undue', the decision-maker must also take into account any compassionate or compelling circumstances in order to decide whether to waive the health requirement. The Procedure Advice Manual lists compassionate and compelling circumstances to be considered as follows:

- the extent of social welfare, medical, hospital or other institutional or day care likely to be required in Australia;
- the education and occupational needs of, and prospects for the applicant in Australia over the whole period of intended stay;
- the potential for the applicant's state of health to deteriorate, taking into account not only the known medical factors but also influences such as the strains of adjusting to a new environment, life-style, occupation etc (as applicable to the visa class and the individual);
- the overall lifetime (or lesser period according to length of stay) charge to Australian public funds;

- the willingness and ability of a sponsor, family member or other person or body to provide care and support at no public cost;
- factors preventing the sponsor from joining the applicant in the applicant's own country;
- whether there are Australian children of the relationship who would be adversely affected by a decision not to waive;
- the location and circumstances of family members of the applicant and the sponsor;
- the merits of the case e.g. the strength of any humanitarian or compassionate factors (reasonable weight to be given to humanitarian circumstances). (DIMIA, 2003: Criteria 4005-4007, Section 77)

The possible circumstances that may arise in any individual application are not limited by this list. The question the decision-maker should be asking is whether the *actual* cost involved in caring for the applicant is 'undue' when balanced against these compassionate and compelling circumstances.

A recent trend seems to be developing in some decisions of the MRT, in that a great deal of weight is being given to the question of whether resettlement is available for the sponsor in the applicant's home country, and the availability of medical care in that country. There is no doubt that under the guidelines these are both relevant questions – or more to the point it is a compelling or compassionate reason to consider *granting* a visa if the sponsor cannot relocate to the applicant's home country, or if returning an applicant to their home country would mean that it was unlikely that they would receive adequate medical care.

If an applicant can return with their nominator to the applicant's home country, where the applicant (and, if relevant, the nominator) will both receive adequate health care, is the cost of medical care then an undue cost for Australia? Some of the recent decisions of the MRT seem to be suggesting this. It is a way of finding additional reasons to justify a cost being undue.

The obvious result is that a person who will not contribute to Australia in any economic way, but comes from a country unable to provide medical care, will be a justifiable cost, while a highly educated and productive applicant with skills needed in Australia, and a high earning capacity, will be an undue cost. This is surely not the intention of the legislation. It disadvantages people with an ongoing, but manageable, medical condition, where they may have many years of valuable contribution to make to Australia.

Are HIV-positive applicants treated differently?

There is little doubt that HIV-positive applicants for permanent residence have the potential to place additional financial burdens on Australia's health care and community support infrastructures. It is both sensible and pragmatic to have an immigration policy with a health requirement that aims to reduce these burdens

and protect their long-term viability. It is equally sensible to build into the policy a safety mechanism, namely the health waiver, whereby a small class of persons are able to migrate to Australia because of compelling compassionate or humanitarian factors, or their links to Australian citizens and permanent residents.²⁹

There is currently a discordance between immigration policy and the manner in which it is administered by the Department, in so far as HIV-positive applicants are routinely rejected at the primary stage of the application process. This *prima facie* rejection of HIV-positive applicants tends towards the conclusion that they are being treated differently and arguably in a discriminatory manner. Applications from HIV-negative applicants with similar circumstances are generally finalised at Department level. However, HIV-positive applicants must appeal to the MRT to obtain a result in which migration law and policy is correctly applied to the individual circumstances of the applicant.

This disparate treatment is in spite of the fact that Australian law recognises HIV/AIDS as a category of disability³⁰ and prohibits treatment or proposed treatment of a person with HIV/AIDS that is less favourable than that of a person without HIV/AIDS in similar or not materially different circumstances.³¹ However, migration decisions are exempted from protections afforded by disability discrimination legislation.³²

It is difficult to say whether all applications in which the health waiver could be applied are rejected at the primary stage, because the Department (citing privacy laws) continually refuses to release figures that would enable objective scrutiny of all applications across all diseases and conditions involving the health waiver. However, figures could be provided devoid of any identifying information.

What is known, however, is that the Department rejects an overwhelming majority of applications from HIV-positive applicants at the primary stage. This exposes the Department to the criticism that their practices are discriminatory and are based on anti-HIV sentiment – whether by design or maladministration. Indeed, this is reinforced by the fact that a majority of primary stage refusals involving HIV-positive applicants are overturned at the MRT.

The Minister recently revealed that 20 of the 22 waiver applications from HIV-positive applicants were granted in 2002/2003.³³ Whilst this demonstrates that HIV-positive applicants are succeeding in their applications, it disguises the fact that to succeed these applicants have had to endure departmental rejections and successfully appeal to the MRT.

The effects

The departmental practice of rejecting applications from HIV-positive applicants at the primary stage adds to the stigma and prejudice that people living with HIV/AIDS continually experience in their lives. But, more importantly, it potentially denies applicants the opportunity to have their application lawfully

determined. Some may simply abandon their application when refused at the primary stage because of fear of disclosure and/or discrimination that they may encounter in pursuing the matter further. Further, an HIV-positive applicant may fail to appreciate their right of appeal or be unable to afford the cost of an appeal to the MRT.

Some off-shore applicants ('refugee' and humanitarian applicants) have no right of appeal, nor even a right to be given reasons for the rejection. Thus the departmental practice of refusing applications at the primary stage effectively denies any real opportunity for their application to be determined according to law. Indeed, the practice may encourage HIV-positive asylum seekers to travel to Australia to seek effective protection under the Refugee Convention because on-shore applicants are not subject to the health requirement whereas off-shore applicants can only succeed if the health waiver is granted – which is extremely unlikely given current departmental practice if the on-shore experience is indicative.

Many social and financial implications stem from the fact that applications involving HIV-positive applicants may take many years from lodgement to determination. The applicant and their partner (the majority of cases are spousal or interdependent applications) live under a cloud of uncertainty, making any sort of future planning difficult, and placing the relationship under an undue amount of stress. It is also an unwelcome stress for an HIV-positive person with a compromised immune system.

Whilst waiting for the application to be determined, an applicant is granted a bridging visa. However, it can be difficult to find permanent work because employers generally prefer Australian citizens or permanent residents. This may cause financial hardship, missed career opportunities, and contribute to emotional stress.

Many applicants abandon their applications because either the relationship with the nominator/sponsor breaks down, or they simply decide that it is too difficult to continue. As Justice Michael Kirby eloquently points out 'all too often the delays, the resistance, and the frustration [in the process] take a toll on the human being involved'. (Hart, 2002: ix)

Other countries

The United States has one of the world's most restrictive policies regarding entry of people with HIV/AIDS.³⁴ Since 1987, it has been illegal for any person with HIV/AIDS to enter the US even as a tourist because it is classified as a disease of public health significance. This is despite the fact that both the United Nations Programme on HIV/AIDS and the United Nations Human Rights Commission have said that there is no public health rationale for restricting liberty of movement or choice of residence on the grounds of HIV status.

Since 1996, people with HIV/AIDS have been able to apply for an HIV visa waiver to travel to the US, but in reality few do so because of the stigma and fear of disclosure. Anecdotal reports indicate that US customs officers are trained to identify antiretrovirals, and repatriations of HIV-positive tourists still occur. (NAM, 2004: 1)

In Canada, the situation is almost identical to Australia in that people with HIV/AIDS can travel to Canada and may obtain permanent residence in certain limited circumstances. (Canadian HIV/AIDS Legal Network, 2003)

The United Kingdom does not currently preclude people with HIV/AIDS from entering or staying permanently. However, recent inflammatory and pejorative media coverage has led to a closed Cabinet Office inquiry into 'imported infections' which may recommend mandatory testing – thus bowing to media pressure and the perception that migrants and asylum seekers are overburdening health and social welfare infrastructures. Interestingly, the All-Party Parliamentary Group on AIDS has declared that mandatory testing would only further stigmatise HIV/AIDS with an accompanying negative impact on public health. (All-Party Parliamentary Group on AIDS, 2003)

Up until recently, New Zealand did not have a system of mandatory testing and relied on self-reports when assessing claims for permanent residence. However, it recently announced that it would ban people with HIV/AIDS from migrating because the disease could be contagious and is costly. However, New Zealand will retain a health waiver similar to Australia.

Concluding comments

Australia's immigration response to HIV/AIDS is sensible and measured in so far as it endeavours to balance the compassionate circumstances of an HIV-positive applicant with Australia's burgeoning health care and community support budgets. The result is an immigration policy that situates HIV/AIDS within a broader policy objective which aims to reduce the financial burden of health care and community support needs that may accompany migrants and asylum seekers with complex and on-going health issues.

However, there is a widely held perception that HIV/AIDS will automatically lead to refusal of a permanent visa, and the Department does indeed refuse to exercise the available health waiver at the primary stage in an overwhelming majority of cases involving HIV-positive applicants. This legitimately leads to speculation that the policy is based on anti-HIV sentiment and that departmental decision-makers are not exercising sound judgment under the policy. This criticism is reinforced when one is cognisant of the high rate of departmental decisions being overturned on appeal at the MRT.

To counter the allegation that anti-HIV sentiment forms part of immigration policy the Department should respond to the longstanding request from lawyers

and community organisations and produce statistics detailing the use of the health waiver involving all disease and conditions in all classes of visa in which it is available. This would allow an effective and transparent comparison and critique of the manner in which the law is being administered at the departmental level.

HIV/AIDS does not automatically lead to a refusal of a permanent visa. Australia's immigration policy does envisage that HIV-positive applicants with sufficient compelling and compassionate circumstances be granted permanent visas. Lamentably, it seems that the only way for an HIV-positive applicant to be granted a permanent visa in a class in which the health waiver applies is to engage an appeal process which is complicated, lengthy, costly and stressful.

This results in a number of negative consequences for HIV-positive applicants. Firstly, it means that where there is no right of appeal, for example, off-shore 'refugee' and humanitarian applicants, the HIV-positive applicant will be refused a permanent visa merely because of where they applied rather than the merits of their case. Secondly, engaging the appeal process is not an easy choice for an HIV-positive applicant as such a process may involve confidentiality and disclosure issues. Thirdly, some HIV-positive applicants, whether for personal or cultural reasons, do not feel empowered to take on government bureaucracy and thus simply walk away when refused at the primary stage by the Department.

That said, the manner in which the law is administered at the departmental level needs improving so that HIV-positive applicants do not have to engage an appeal process in order to have their applications properly determined according to law and policy.

Les Szaraz has degrees in law and international studies.

Notes

- 1 For a general outline of the health requirement, see DIMIA (2002).
- 2 See: DIMIA, Form 1163i, *Health requirement for temporary entry to Australia*, revised Nov. 2003; DIMIA, Form 1071i, *Health requirement for permanent entry to Australia*, revised Nov. 2003. [Available at: www.immi.gov.au.] See also Section 65(1)(a)(i) & (ii) of the *Migration Act 1958* and Regulation 2.25A of the *Migration Regulations 1994* which incorporates the Schedule 4, 4005-4007 health criteria.
- 3 On-shore asylum seekers invoke Australia's international obligations under the 'Refugee Convention' (UN Convention Relating to the Status of Refugees 1951 and the UN Protocol Relating to the Status of Refugees 1967) and are granted what is called a protection visa. Off-shore asylum seekers have usually been identified by the United Nations High Commissioner for Refugees (UNHCR) as persons in need of protection and resettlement. Such persons can apply for a 'Refugee' (Subclass 200) visa, but this is somewhat anomalous because the requirements for this visa, as prescribed in the *Migration Regulations 1994*, are narrower than that contained in the Refugee Convention. For example, there is a health requirement, and persecution must have actually occurred rather than be feared. For a more thorough treatment of this issue see Germov and Motta. (2003: 62-64)

- 4 Technically speaking New Zealand citizens applying for the temporary Subclass 444 Special Category visa are also exempt from the health requirement. However, they must not be a 'health concern non-citizen', according to s.32(2)(a)(ii) of the *Migration Act 1958*. Section 5(1) of the *Migration Act 1958* defines this as a non-citizen who is suffering from a prescribed disease or a prescribed physical or mental condition. Pursuant to Regulation 5.16 of the *Migration Regulations 1994* the only prescribed disease is untreated tuberculosis.
- 5 See Criteria 4005, 4006A(1) and 4007(1) of Schedule 4 of the *Migration Regulations 1994*.
- 6 See Regulation 1.03 of the *Migration Regulations 1994*.
- 7 The only exceptions are two classes of temporary visas that involve the 4006A health criteria. These are Subclass 418 Educational and Subclass 457 Business (Long Stay) visas. The health requirement may be waived where the applicant's employer gives a written undertaking to meet all the costs related to the disease or condition that causes the applicant to fail the health requirement. See Criteria 4006A(2) of Schedule 4 of the *Migration Regulations 1994*.
- 8 If the application is for a permanent visa from a country specified by Gazette Notice and there is no information known to DIMIA or declared on the applicant's application form, then there is no requirement for DIMIA to seek the opinion of the MOC: Reg 2.25A(1)(b) of the *Migration Regulations 1994*. Note, however, that no country has been gazetted for the purpose of this regulation.
- 9 See Regulation 2.25A(3) of the *Migration Regulations 1994*.
- 10 A few temporary visas contain the health waiver: Subclass 447 Secondary Movement Off-shore Entry; Subclass 449 Humanitarian Stay; Subclass 450 Resolution of Status – Family Member; Subclass 451 Secondary Movement Relocation; Subclass 461 New Zealand Citizen Family Relationship.
- 11 For detailed information see DIMIA, Form 1163i, *Health requirement for temporary entry to Australia*, revised November, 2003. [Available at: www.immi.gov.au.]
- 12 This means any country on the African continent other than Libya, Morocco, Tunisia, Algeria and Egypt.
- 13 Subclass 866 Protection visa and Subclass 785 Temporary Protection visa. These applicants do undergo health screening, but it is not relevant to the determination of their application for a protection visa.
- 14 As at 1 January 2004.
- 15 Subclasses 100/309/801/820.
- 16 Subclass 300.
- 17 Subclasses 110/310/814/826.
- 18 Subclasses 101/802.
- 19 Subclass 445. This is for a child of a provisional visa holder, that is, Subclasses 309/310/820/826.
- 20 Subclasses 102/802.
- 21 Subclass 151.

- 22 Subclass 832. This is for those who spent the greater part of their formative years in Australia or 'innocent illegals' who entered Australia before turning 18 and have become unlawful non-citizens through no fault of their own.
- 23 'Subclasses 200/201/202/203/204. These applicants are usually identified and recommended for re-settlement by the UNHCR.
- 24 Subclasses 787/852. This is only available for witnesses in relation to people smuggling.
- 25 Subclasses 890/891/892/893.
- 26 Legally the Minister is the person who waives the health requirement on advice of the Department.
- 27 See Criteria 4007(2) of Schedule 4 of the *Migration Regulations 1994*.
- 28 Under the *Migration Act 1958* and the *Migration Regulations 1994* the Minister is designated as the person making the decision. However, in practice departmental delegate (s.496) usually makes the decision. When an appeal goes to the MRT the tribunal member steps in the shoes of the Minister and looks at the merits of the case afresh.
- 29 The recent inclusion of the health waiver in business skills visas represents a radical departure from previous criteria for including the health waiver in a visa class. Now applicants who are willing to invest a significant amount of money who fail the health requirement may be able to obtain permanent residence notwithstanding the fact that they may not have any links with Australian citizens and permanent residents.
- 30 Section 4 of the *Disability Discrimination Act 1992* (Cth) defines disability as including the presence in the body organisms causing or capable of causing disease or illness. This includes previous, present, future or imputed disability.
- 31 Section 5 of the *Disability Discrimination Act 1992* (Cth).
- 32 Section 52 of the *Disability Discrimination Act 1992* (Cth).
- 33 Correspondence from the Minister, *Sydney Star Observer*, 7 July, 2004, p. 6.
- 34 Section 212 of the *U.S. Immigration and Nationality Act*.

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Shooting high: the saga of AIDS vaccine development

by **Bridget Haire**

In 1984, at the time that the AIDS-causing pathogen HIV was identified, Ronald Reagan's Secretary of Health and Human Services, Margaret Heckler, promised that a vaccine would be on its way within two years.¹ Twenty years on there is no such vaccine, and only one candidate has yet been tested for efficacy. Meanwhile, global HIV infections are estimated at 16,000 a day. Nineteen years after Heckler's announcement, on 24 February 2003, the results of the first AIDS vaccine efficacy trial were announced. The vaccine did not show a statistically significant reduction in HIV infection. Although another 30 or so preventive AIDS vaccine candidates are in the pipeline, we are still years, if not decades, away from an even partially effective product. So what is taking so long?

An article published in 1983 by US AIDS activist Larry Kramer '1,112 deaths and counting' makes no mention of an AIDS vaccine. (1983) Kramer argues for community mobilisation and political commitment in the search for a cure, but doesn't mention the 'V-word'. I think this was a question of priorities rather than an oversight. For activists, treatment for the sick was the overwhelming priority in the rich countries hardest hit by the first wave of the epidemic in the 1980s. Condoms or abstinence plus needle and syringe programs were the apparent answers for prevention. It is significant that AIDS was first identified in a stigmatised population under a conservative administration in the US. There was offensive rhetoric about 'innocent' victims, and those whose illness was deemed the wages of sin. In this context it is understandable that activist pressure was focused upon asserting the humanity of the HIV-infected and fighting for treatments rather than biomedical prevention.

It took 13 years for drug development to get to a point where the treatments could really be called life-saving. AIDS in high-income countries then became something of a goldmine for the pharmaceutical industry – people with HIV were encouraged to start treatment before immune dysfunction set in, on the theoretical premise that hitting the infection hard before it took hold would be the most effective tactic. While the eradication concept sank relatively quickly, 'chronic manageable infection' became the new 'buzz term'. For most of the world, all this meant nothing. Condoms, let alone protease inhibitors, are out of reach for most people in resource-poor countries.

Do we need a vaccine?

Behavioural prevention works, as the containment of HIV infections in Australia attests. Needle and syringe programs and condoms in high-risk populations – gay men and sex workers – have kept Australia’s epidemic a small one. Part of this is due to synchronicity – behavioural prevention started in earnest very early in the epidemic. With regard to mother-to-child transmission, biomedical prevention (treating both mother and baby and avoiding breastfeeding) has reduced this in recent years to nearly zero, and heterosexual transmission has been on a very small scale in this country. Nevertheless, infection rates in identified at-risk populations are increasing. Behavioural interventions work imperfectly, and not necessarily indefinitely.

AIDS vaccines are a necessary and long-overdue component of the fight against AIDS, and they need to be part of a package of prevention and treatment technologies. Medical research is not humanitarian aid, but as HIV is endemic in areas of extreme poverty, this arguably creates responsibilities for research. The result of a particular research project is necessarily uncertain, but even if the candidate product fails, the outcome of a project can be beneficial to the communities involved if the process itself increases availability and uptake of other HIV prevention and treatment options. At the very least, AIDS vaccine researchers are responsible for ensuring that research does not add to injustice.

The transmission of HIV is readily preventable, if one looks at it on a merely mechanical level. But human desire is a complex phenomenon, and the social and cultural forces that regulate and channel that desire cannot be changed overnight just because of some pesky microbe. Behavioural prevention has a contraceptive side effect. Where this effect is unwanted, condoms are clearly inappropriate. Furthermore, as the slow increase in infection in Australia suggests, significant numbers of men who are at risk of HIV do not want to use condoms for sex on an ongoing basis.

With condoms as the only reliable protection from the sexual transmission of HIV, women are left particularly vulnerable, and socio-economic and political inequality adds to this vulnerability. In the absence of either an effective microbicide or vaccine, there is no woman-controlled undetectable prophylactic against the virus. (‘Female’ condoms are expensive, detectable by male partners, and noisy.) To compound matters, women are more biologically vulnerable to infection than men in heterosexual intercourse. All these factors should place the development of an AIDS vaccine firmly on the feminist agenda.

An effective AIDS vaccine has to work in the real world where the majority of infections are taking place. That means that vaccine needs to be affordable, to be readily transportable without requiring refrigeration and, ideally, not require multiple dosing. (Not needing to be injected would be another bonus for user-friendliness.) As vaccine research and development is expensive and takes

time, clearly candidate vaccines that could work well in real-world scenarios and those that are effective against the most prevalent strains need to be prioritised, and novel forms of administration such as mucosal application rather than injection (intra-nasal, for instance) may give a useful edge. But as yet, these kinds of refinements are far away. No product has yet shown effectiveness in preventing either HIV or AIDS.

Ethical challenges

Testing efficacy is a monumental task. To test the effectiveness of an AIDS vaccine, some people need to be infected with HIV. I hasten to add that research participants in liberal democracies are not deliberately infected with life-threatening viruses, so a delicate ethical path needs to be trodden to design trials that can produce results (which requires seroconversions), but which do not encourage participants to seroconvert. This means that, of necessity, AIDS vaccines need to be tested in populations of high HIV incidence which, in geographical terms, means the resource-poor world, where AIDS is endemic – Africa in particular and parts of Asia.

At-risk populations from the developed world – such as homosexually active men who do not always practise protected sex in risk situations, and the sexual partners of positive people – have and will continue to form part of efficacy-testing cohorts, but the majority of participants will be recruited from the world's poorer nations. The potential for exploitation is explosive.

Expectations of ethical practice in medical research have progressed a long way since Edward Jenner tested his theory that cowpox infection may protect against the deadly smallpox. (1801) Jenner simply made his observations, devised a test, waited for the results and then re-tested to check for reproducibility. Never mind that he was placing another human life at risk – the life of a 'healthy boy' at that (sounds like a minor and I bet he didn't give informed consent). Jenner's discovery ultimately saved millions of lives, but his methods are analogous to experiments carried out in Nazi concentration camps.

Nazi war crimes involving human experimentation were the catalyst for the codification of medical research ethics on human subjects. Following the Nuremberg trials, the Nuremberg Code (Directives for Human Experimentation) was produced, which formed the basis of the ethical code adopted by the World Medical Association in 1964 now known as the Declaration of Helsinki. This document has undergone revision several times, most recently in 2000.

Contemporary medical research ethics are designed to protect the vulnerable from exploitation. Too frequently, submitting research protocols for ethical review and meeting ethical codes of practice is characterised as 'jumping hurdles' rather than as a necessary and integral part of ensuring that research is just and humane. Indeed, such processes have been inadequate to prevent scandalous exploitation

of research participants in developing countries as recently as 2002. (Stephens, 2002)

The principles of ethical research are articulated in different ways. The Belmont Report (1979) codifies these as respect for persons, beneficence and justice. In application, respect for persons covers informed consent in all its complexity (including voluntariness, comprehension, capacity to consent and confidentiality), beneficence (the assessment of risks and benefits), and justice (the selection of research subjects so that the benefits and burdens of research are distributed fairly).

Fierce debate accompanied the latest revisions to the Declaration of Helsinki, as it was proposed that the clause stating that participants in the control arm of a clinical trial should be ensured the 'best proven' standard of care should be altered to the 'highest attainable' standard of care. This would effectively endorse a sliding scale of control arms, with participants in lesser-developed countries needing only to be offered such care as was available in their country (which could be nothing). This would make research in poor countries faster and cheaper, but it would also perpetuate global injustice.

This debate had particular relevance to research into biomedical prevention of HIV, which encompasses also topical microbicides, the use of antiretrovirals to prevent vertical transmission, and pre- and post-exposure prophylaxis. In the 1990s, an ethical furore erupted over studies on vertical transmission which used a placebo control arm despite the proven efficacy of the ACTG 076 protocol.² The then editor of the *New England Journal of Medicine*, Marcia Angell, denounced the trials as unethical, comparing them to the now infamous Tuskegee study where generations of black American men were left with untreated syphilis while effective treatment was available, so that the natural history of the disease could be studied. Ethicists Peter Lurie and Sidney Wolf backed Angell. In turn, those who supported the trials called Angell, Lurie and Wolf 'ethical imperialists' who would halt important medical research – and access to affordable treatment – by imposing impossible standards on it.

At the heart of this controversy lie two very important – and seemingly conflicting – issues. On the one hand, there is a very real and demonstrable need for participants in medical research to be protected from exploitation. Endorsing lower standards of care in poor countries effectively sets the poor as convenient guinea pigs for the affluent. On the other hand, there is a need to establish affordable and sustainable treatment/prevention options for specific local contexts, where grafting a protocol from a high-income context such as the US simply doesn't address the realities of the situation. This is where applying a code of practice like the Declaration of Helsinki is not always particularly useful, whereas applying the principles of the Belmont Report, with special emphasis on the principle of justice, can be illuminating.

With particular reference to the vertical transmission trials, the argument that the ACTG 076 protocol was not affordable is specious in the context of a clinical trial. The cost of treatment is not immutable. Multinational pharmaceutical companies can afford what they want to afford, and the pricing of antiretroviral drugs depends on what the market will pay. But the argument that women in resource-poor countries present far later for antenatal care and therefore the ACTG 076 protocol is impractical is a reasonable one and provides some justification for aspects of those trials (although I don't believe it justifies a no-drug placebo arm in any context).

Similarly, vertical transmission trials that aim to find a formula for reducing mother-infant transmission while allowing breastfeeding are very important in some parts of the world. But there is a significant difference in devising trials that respond to the specific needs of an under-privileged population and using such a population to get a quick answer to a research question when the benefits do not flow to those research participants and their communities.

How does this all relate to HIV vaccines? The ethical controversies over vertical transmission trials spilled into debate over vaccine research. Specifically, in a vaccine efficacy trial, the question was asked, what kind of care should be available to those who seroconvert? UNAIDS ran a series of workshops around the world on the ethics of HIV vaccine trials in 1998, and this issue was a particular sticking point. Some participants from Uganda and Thailand argued that if antiretrovirals were not available in the country running the trial, provision of them to trial participants who seroconverted would be an 'undue incentive' and would undermine the voluntary nature of participation. (Kahn, 1999) Brazilians however, were particularly adamant that antiretrovirals must be provided.

In an article on the UNAIDS meetings, Patricia Kahn offers the following analysis:

The three regions each had a clear view. Asia and Africa, home to most of the world's hardest-hit countries – which have the biggest stake in getting an effective vaccine rapidly – accepted the 'highest practically attainable' standard of care for trial volunteers, largely out of concern that requiring triple-drug therapy would create a huge barrier to mounting any trials. In contrast, participants at the Latin American workshop (led by representatives from Brazil, where triple-drug therapy is widely available, but including several representatives from countries where it is not), along with the US-based advocacy group, Public Citizen, argued that trials must provide triple-drug therapy, according to existing ethical guidelines (and ideally continue them for the person's lifetime). The outcome was a stark illustration that, with few exceptions, 'a country with 20% of the people infected sees things very differently than a country that perceives AIDS as a treatable problem,' says [UNAIDS' Jose] Esparza. (1999)

Significantly, however, these workshops were prior to the Durban International AIDS Conference of 2000, where assumptions of the ‘unaffordability’ of antiretrovirals were subjected to intense international scrutiny. Since 2000, pressure to drop drug prices and remove unreasonable barriers to generic production and distribution of life-saving drugs have mounted in intensity. I would argue that the sense of what is possible has changed markedly now, and that the concept of a double standard – one for the rich and another for the poor – is less palatable all round. The notion of treatment for the sick being an ‘undue’ incentive does not, I think, bear scrutiny either. It is in my view entirely just and appropriate that people who bear the risk of research that aims to alleviate the global burden of AIDS should be able to access proven life-extending treatment.

Nevertheless, in the one efficacy trial that has taken place to date (of VaxGen’s AIDS-VAX), seroconverters in Thailand were only supplied with the highest attainable treatment in Thailand at the time (double nucleoside therapy) rather than triple therapy with a protease inhibitor. This was despite AIDS-VAX researcher and champion Don Francis wanting the higher standard of therapy to be available. (Thomas, 2001) The Thai authorities secured many benefits for Thai research infrastructure through their negotiations around this trial, but the participants themselves did not fare so well.

Most of the AIDS vaccine trials taking place in the world now are at preliminary stages, where the hard-core problem of proving efficacy is not yet an issue. Ethical and human rights issues are also at stake in preliminary trials, such as ensuring that the participant truly understands and consents to the risk that he or she is undertaking, the level of safety and quality assurance of the experimental vaccine and protections for the participants if a serious adverse reaction occurs. Real informed consent and safety concerns matter across the spectrum of human testing, but safety and the participant’s understanding of risk is particularly significant in early trials where the compound has not yet been tested in human bodies.

‘Risk’ in an HIV vaccine trial is not only from the experimental product itself, but also the risk that the trial participant may feel that he or she has an immunity to HIV as a result of participation. The onus is on researchers to ensure that participants fully understand that the product does not offer any proven protection from HIV infection. This is a critical function of the informed consent process.

In the early-stage Australian vaccine trial nearing completion in Sydney, there were various levels upon which this point is stressed. All participants, who are at low risk of HIV infection, were supplied with written information plus access to discussion with the trial investigator and/or a community AIDS organisation. Before the participants were vaccinated, their understanding of the trial process was tested, and then throughout the trial safe-sex messages were reinforced in literature provided on aspects of participation in clinical research.

Australia's involvement

Australia's 4th National HIV/AIDS Strategy commits to 'a national vaccine effort' relating to vaccines for prevention and treatment of HIV/AIDS with four main components including a 'commitment to conduct population efficacy trials of a coordinated prevention strategy that incorporates vaccines alongside education and treatment programs'. (2000, 26) The question is now should we be moving towards a separate National Vaccine Plan model such as that which exists in Thailand and which is being pursued in Canada? Such a plan would detail roles and responsibilities, including human rights/ethical factors, community involvement, delivery and access issues. Guidelines for whether or not partially effective vaccines should be approved for use in this country, and principles guiding Australia's role in conducting vaccine trials in the region are two areas that urgently require considered policy development.

The early-stage (phase I/II) vaccine trial taking place in Sydney in 2003/2004 is funded by the US National Institutes of Health and is a research collaboration with Thailand, where later trials of a modified construct will take place. While this is the first trial of an Australian vaccine construct, it is not the first time that Australians have participated in an AIDS vaccine trial. In 1993, 24 people at high risk of HIV infection participated in another I/II trial at St Vincent's hospital. This trial was of a peptide vaccine based on the V-3 loop of GP 120, made by United Biomedical Inc. It was found to be safe, but it did not produce sustained or robust immunological response. Further development was halted. (Kelleher, 1997)

Preliminary results from the current vaccine trial are also disappointing, showing at best a modest and inconsistent immune response. (Emery, 2004) Further development of the related vaccine based on a Thai subtype is still expected to proceed. However, plans for a larger-scale trial have been reduced to a small safety/immunogenicity study following the poor immune response elicited in the Sydney trial.

The *nef*-gene discovery

Australia's links to AIDS vaccine research began before the 1993 trial. The discovery of the Sydney Blood Bank Cohort was arguably one of the most exciting – and ultimately disappointing – events in the search for an AIDS vaccine. As part of the tracing of contaminated blood unwittingly donated in the 1980s, a group of eight people were discovered who could trace their HIV infection to a single donor (a further eight were identified who had already died of their pre-existing conditions, and three of the original eight died subsequently). Neither the five survivors nor the donor had any HIV-related immune dysfunction. Genetic sequencing revealed that these people were infected with an unusual strain of HIV from which the *nef*/LTR gene was deleted. (Learmont, 1999) It was hoped that the deletion of this gene might be the key to unlocking the pathogenic capacity of HIV.

Live and life-like vaccines

John Mills, director of Australia's Macfarlane Burnet Centre, proposed making an infectious molecular clone of the *nef*/LTR-deleted virus and beginning testing. This was at the time that pressure was mounting for the development of a live-attenuated (weakened) HIV vaccine, on the basis that such a vaccine has the greatest likelihood of efficacy. The Sydney Blood Bank Cohort discovery buoyed hopes that a genetic mutation could effectively destroy HIV's disease-causing mechanism.

The elegance of Mills' vaccine proposal was that the infectious clone would be a more stable alternative to a live virus vaccine, which usually requires at least refrigeration and probably freezing, and would also be less dangerous. However, hopes were dashed when it emerged that members of the Blood Bank Cohort were beginning to show signs of the immune dysfunction that precedes AIDS. The *nef*/LTR-deleted virus was not non-pathogenic, it just worked at a slower rate. (Herring, 2001) Vaccinating people with a clone of this virus would be inoculating them with a slower life-threatening virus than regular HIV, but a life-threatening virus none the less.

By 1997, the International Association of Physicians in AIDS Care was asking doctors to sign up as people willing to take the risk that a live vaccine product would inevitably pose. (Nary, 1997) But the campaign for testing a live attenuated vaccine soon died as evidence mounted of the likelihood that a live HIV vaccine could cause disease. It was apparent that a trial of such a product would not get regulatory approval.

While the live attenuated vaccine concept still has its champions – Ron Desrosiers, who developed such a vaccine being the most famous and outspoken of these (Gold, 1997: 1), it is unlikely that such a product will ever be tested in humans.

The ethical argument against testing a live HIV vaccine is the unacceptable burden of the possibility of such a test resulting in some participants being infected with a life-threatening virus (through the vaccine reverting to wild-type in an individual, or because the vaccine causes disease over a longer period of time). While this has overtones of paternalism, it is not limited to medical research, but pervades societal control (in a protective sense) over the individual body.

Although on a commonsense level most of us feel we 'own' our bodies and their various components, in a legal sense in Australia this is not quite accurate. The law prevents us from fragmenting and commodifying ourselves – we cannot sell our blood, limbs or organs. The individual body forms part of the body of citizenship. While citizens can join the armed forces and risk life and limb in armed combat, they cannot opt to participate in life-threatening medical research unless it is deemed that the risk has been minimised and that the likelihood of individual benefit (not the benefit to humanity as a whole) is at least as great as the individual risk.

Partially effective vaccines

Live-attenuated vaccine concepts are held to be the most likely to prevent HIV infection. The problems of testing them produced a shift to looking more at vaccines that would be capable of preventing disease rather than infection itself.

HIV infection does not kill. Immune suppression, and its attendant opportunistic infections, is the killer. The prevention of infection, ‘sterilising immunity’, is often thought about as the gold standard in vaccines. In many diseases, however, it is quite unnecessary to prevent infection – a vaccine that renders the infection non-pathogenic does the job. Scientifically, a vaccine that prevents disease rather than infection is thought to be a more achievable goal. (Cooper, 2002)

Mathematical modelling has shown that a partially effective AIDS vaccine (30–50% effective – a ‘low-efficacy’ vaccine) introduced today would have a far more significant effect than one that offers more protection (80% or above) introduced later. (IAVI, 2000: Appendix 3). This argument may lead to the fast-tracking of any AIDS vaccine that shows low efficacy in at least some countries, possibly in sub-Saharan Africa. At present, the argument remains academic, as no vaccine has yet shown efficacy in humans.

‘Partially effective vaccine’ is a complex concept, and in fact can have multiple meanings. It can be used to refer to a vaccine that is only effective in preventing infection in some people, or it can be used to refer to a vaccine that is effective in preventing AIDS-related disease but not HIV infection. Many of the more promising candidate vaccines being tested now are likely to ‘work’ in this way, as they rely on immune responses that kick in after initial infection, such as cytotoxic T-lymphocytes (CTL).

Proving the efficacy of a vaccine that prevents disease, but not infection, poses particular scientific challenges. Logically there would need to be some reliance on surrogate markers. It is not feasible to conceive of a trial that would follow a large cohort of people for the period of time required to show that the vaccination rendered the infection truly non-pathogenic. A vaccine that resulted in significant delay of AIDS-related immune damage and disease would nevertheless be an enormous public health advance in areas where AIDS is endemic.

The benefits of a partially effective vaccine in countries where behavioural prevention is currently containing infections are less clear-cut, particularly where the efficacy is operating at the low end of the ‘partial’ scale. As the concept of vaccine is broadly understood to mean protection from a specific infection, introducing a partially effective vaccine would require massive educational efforts to ensure that the limitations of such a vaccine were well understood.

Inevitably, without wishing to sound paternalistic, such a vaccine would result in some increase in risk behaviour, so the benefits of introducing a vaccine with very low efficacy need to be weighed against an increase in risk. In some populations, a low-efficacy vaccine may actually have a detrimental effect on public

health. The decisions about where such a vaccine should be licensed are complex for regulatory bodies. What degree of efficacy makes the benefits outweigh the risk? With regard to Australia, this is an area in which further social research into attitudes to vaccines in at-risk populations may be illuminating.

Placebo arms

Once a vaccine is shown to be partially effective, another level of complication is added to subsequent AIDS vaccine efficacy trials. According to the Declaration of Helsinki, a new treatment should be measured against the current ‘best known’ intervention, which is known as the ‘standard of care’ or control arm. Currently in AIDS prevention, this means optimal behavioural prevention: access to condoms and lubricant (and/or clean injecting equipment), and appropriate education to back these. Arguably any vaccine proved partially effective should be added to these, alongside education about its limitations.

There are also arguments against using a low-efficacy vaccine as a control, however. If the ‘standard of care’ vaccine shows very low efficacy, the possibility such a vaccine could actually increase seroconversions due to increased risk behaviour applies to the trial cohort. (Social research into the potential trial population could be useful, but I suspect that it may be deemed frivolous in a very resource-poor setting where there are major competing demands for AIDS-related spending.)

There is also a scientific argument against using a very low-efficacy vaccine as standard of care – in some instances it is biologically plausible that such a vaccine could blunt the immune response to a later, more effective vaccine. Exposure to a low-efficacy vaccine would also certainly exclude trial participants from later trials that again are likely to be of more effective products. (It is also possible that prior exposure to an early vaccine may enhance the immune response to a later one.)

This potential modulation of the immune response is also an issue in vaccine trials, and participants need to be informed that participation in one trial will probably preclude participation in any other (unless they can show that they were on the placebo arm), and may even alter the body’s response to any subsequent proven AIDS vaccine.

Biomedical bias must also be considered: might a low-efficacy vaccine be used as a substitute for rather than an adjunct to, the ‘best proven’ protection from HIV infection – behavioural interventions? While this is unlikely to happen overtly, as the precedent has been set that condoms and counselling must be available to participants in efficacy trials, it could happen covertly by under-resourcing behavioural prevention.

There is no ‘one-size-fits-all’ answer to these questions. Ethically the imperative is to ensure that participants get access to the best proven standard of

prevention. This may be behavioural prevention alone, if there is valid scientific concern that exposure of trial participants in the control group to a suboptimal vaccine may cause undesirable immune responses that may not be in the best interests of the participants.

The biological plausibility of the scientific argument would be the pivotal factor in the trial design in this instance. The argument to withhold a suboptimal vaccine on the basis of assumed increased risk behaviour would need to be backed by some evidence that using such a vaccine as a control would indeed affect risk behaviour in that particular population, and this would need both social research and consultation with the communities from which the trial participants were to be drawn to avoid paternalistic assumptions guiding trial design.

Another example of where a proven partially effective vaccine could be reasonably excluded from a subsequent efficacy trial would be where the nature of administering the low-efficacy vaccine itself was so difficult (requiring refrigeration and multiple dosing, for instance) and/or its side effects so significant that it would be unlikely to be usable in that particular population. Basing decisions about the control arm of an efficacy trial purely on expediency from the perspective of the researchers, however, would be unethical. Careful weighing of risks and benefits with regard to the specific situation, and in consultation with communities from whom participants would be drawn are critical to making such decisions.

A further ethical complication may soon emerge as full-scale efficacy trials, statistically powered so that results can be used for making licensing decisions, are replaced with smaller ‘proof of concept’ studies. The reasoning behind the smaller studies makes good sense: with the VaxGen experimental vaccines having failed the efficacy test, and with another enormous (16,000 participant) trial taking place which many experts agree shows little chance of success, there is a limit to how much money and how many people’s lives can be taken up in big trials with poor prospects. A ‘quick and dirty’ (underpowered) trial that can prove whether or not an experimental vaccine works is certainly preferable, given that a negative result is more likely than a positive one.

But should a vaccine prove effective in a smaller trial, the vexed question of re-testing this in a placebo-based trial large enough to satisfy licensing authorities will pose ethical conundrums. If the concept of efficacy has been ‘proved’ to some extent in a smaller trial, then the principle of equipoise – the uncertainty as to whether or not an intervention will work, which is the basis of ethical clinical research – is fundamentally disturbed. HIV vaccine efficacy trial participants are, by definition, vulnerable persons. Are there compensations that could acceptably be offered that would offset the burden of being randomised on such a trial? And who would make such decisions? At the time of writing, this is not an area that has been explored adequately.

Community consultation

There are different models of community consultation that have been used in AIDS vaccine trials. The first and most common is using a community advisory board (CAB) which oversees the research but is made up of individuals from participating communities (some of whom may actually participate themselves in the vaccine trial) and who are independent of the research (i.e. not being paid). The aim of CABs is to ensure that the concerns of the community are foregrounded, and that there is sensitivity to socio-cultural norms.

The model being used for the current Sydney vaccine trial is different. Instead of the community being involved in a consultative way, Australia's peak community AIDS body, the Australian Federation of AIDS Organisations, is actually a partner in the research. This means having a seat at the tables where critical decisions are made, such as within the group that oversees the clinical trial, and having an equal stake in the intellectual property of the candidate vaccine.

Community consultation is not a substitute for informed individual consent, but it is a necessary component of it. True voluntariness is a non-negotiable condition of ethical research. In some cultures, it may be appropriate and necessary to receive broad consent from a community forum in a formal sense prior to seeking individual consent, but it is imperative that individuals are still choosing for themselves and not under some form of covert coercion. Community education and consultation about research projects provides a context where issues pertaining to the research can be discussed and debated by potential trial participants and communities that stand to benefit from the research outcomes, which is highly desirable and arguably essential.

'Community consultation' about significant issues in trial design needs to be meaningful and not tokenistic, so in the event that theories of the immune response form part of the decision-making, the issues need to be made comprehensible to those community members being consulted. This sounds obvious, but it is not necessarily easy and requires much patience and goodwill on both sides.

Clade politics: a real concern or a distraction?

HIV is an extremely mutable virus and has been classified into various subtypes (also called clades). Some of these subtypes have recombined to form new variations again. Certain clades are associated with particular geographical areas, and there is evidence that in areas where there are more genetic variants found, HIV has been in the population longer. (Nyambi, 2001)

Experimental vaccines use parts of the gene sequence from particular laboratory-cultured strains of HIV, and there has been conflict over which clades of HIV are used to make vaccines. For example, in the early period of vaccine research most vaccines in development were based on a B-clade virus, which is predominant

in the US, Australia and Western Europe. This was legitimately a cause of concern. While the correlates of protection are not known, it makes sense that a vaccine based on a particular virus would be most effective against the circulating strain closest to it.

But the consensus now is that there is no direct correlation between the scientific classification of genetic strain of HIV and immune response. Further, experimental vaccines in development now tend to use the conserved regions of the HIV genome – the genes that are the least subject to mutation from subtype to subtype.

In the hypothetical case that vaccine-induced immunity did correlate strictly with genetic classification, this would not constitute a ‘real-world’ friendly vaccine in those regions where the spectrum of HIV clades and their recombinant children are to be found – and it is, of course, these regions that need a vaccine most desperately. ‘Real-world’ vaccines should be, and are, as far as possible, being designed to work across clades.

The question needs to be asked whether too much money is being spent re-making experimental vaccines using different clades for reasons that are entirely unrelated to plausible science.

The significance of clades to vaccine development is yet to be clarified. Chances are that, when the answer comes, it won’t be a simple ‘yes’ or ‘no’. But let’s hope that science, not politics, determines how money is spent on clade-related studies.

Slow progress

While HIV is a global emergency, the pace of AIDS vaccine research has been frustratingly slow. There appears to be a general consensus among all involved, at whatever level, that pace must increase. Why has it been so slow? *Science* journalist Jon Cohen, in his book *Shots in the Dark: The Wayward Search for an AIDS Vaccine* (2001) blames the lack of what he describes as methodical, empirical research with appropriate funding to test out vaccine concepts – starting with simple ones – in a systematic way. Says Cohen:

Study immune response, absolutely. Great to know that stuff. But you don’t have to know that to make a working vaccine. As much as there are advocates for CTLs³, for sexy new antibodies that will be uncovered when you take the dress off over here, nobody really knows the immune correlates of protection. So let’s stop pretending that we do. It’s great that there are people who believe in CTLs, or in neutralising antibodies. They should run with it; carry their vaccine forward. But there’s a clock ticking. We’ve known for years that a 60% efficacious vaccine introduced today will prevent more infections and disease ten years down the road than a 90% effective vaccine introduced five

years later. So there's a great reward in coming up today with a mediocre vaccine that is crudely understood. (IAVI Report, 2001)

The politics of AIDS vaccines too often boils down to greed, desire for self-aggrandisement, refusal to work cooperatively and the profit motive. This is a systemic failure rather than simply due to the personalities involved. It is due to the way that medical research functions both in academic institutions and in the private sector, as has recently been acknowledged by leaders in the AIDS vaccine field. A group of 24 people with an impressive range of expertise in the AIDS vaccine saga have recently authored a paper in the journal *Science* advocating an HIV vaccine enterprise that is coordinated and holds a common vision. The proposal is complex and perhaps utopian, but it is exciting to see a map for a different and more efficient way of progressing research and development. (Klausner, 2003)

The weight of cumulative global HIV infections and the human misery it causes can result in researchers becoming impatient about delays. Ethical processes can become a focus of frustration because, unlike other regulatory processes or practical delays, they can be seen as avoidable. But it has been the politics of science, not the politics of ethics and human rights that has been at the heart of the delays.

Lesson for HCV

Are there lessons to be learned from the development of AIDS vaccines that can be applied to hepatitis C? Clearly the first lesson to be learned from the example of the Reagan administration's rhetoric, compared with its inaction, is vaccine research has to be a serious priority. Commentators who have made a rigorous study of how AIDS vaccine research has been conducted conclude that it has not been sufficiently systematic, but has been driven by the kind of unhelpful competition that results in basic precepts – like finding the best animal disease model – remaining contentious.

Looking specifically at the response in Australia, however, the picture is less grim. There is both expertise and enthusiasm for HIV vaccine development, together with an understanding that a vaccine will not be 'the' answer to the global misery of AIDS, but part of a package of interventions that are needed to address a complex and insidious problem even today.

Australians – Sydneysiders, specifically – are now participating for the second time in an early-stage vaccine trial. The current trial of an Australian-designed product is the result of collaborations between several different universities, the CSIRO and the community sector, with further links extending to Thailand, both in Thai scientific and community sectors. This looks like partnership in practice.

HIV is a deadly pathogen, but it causes disease slowly. Obviously there are similarities to HCV here, although untreated HCV does not result in disease as inevitably as untreated HIV. Unlike HCV, its primary mode of transmission is sexual

with blood-to-blood infections accounting for a significant minority of infections. Both, however, are diseases of stigma and discrimination.

Affected communities in Australia have formed part of the response to both HIV and HCV, although the differences between those communities and how this affects their political operations has not always been well understood. While 'gay man' has operated as a social and political identity prior to AIDS, that is not so for injecting drug users and their partners. The 'HCV community' is an artificial construction of a sub-population who may have little if anything in common other than proximity to drug use at some point, which can be a hidden activity rather than an identity-forming one. The illegality of injecting drug use is a factor in this.

The overlap between HIV and HCV in Australia, with injecting drug use being a mode of transmission for both and injecting drug users and their advocates forming part of the response to HIV, is perhaps a reason why the differences between the two subpopulations have tended to be elided. While I would argue for 'community' participation in any HCV vaccine research, it would be important to understand its diversity and difference from the HIV-affected community rather than assume similarities.

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Notes

- 1 AIDS vaccines are being developed both as preventive agents to be tested in HIV-negative people and as therapeutic agents to be tested in HIV-positive people. Some preventive candidate vaccines may have an application in slowing disease progression in HIV-positive people. This article is predominantly about AIDS vaccines as preventive agents. The term 'AIDS vaccine' is used in preference to 'HIV vaccine' as vaccines in or nearing human testing are more likely to prevent HIV-associated illness – AIDS – than prevent persistent infection with HIV.
- 2 ACTG 076 consisted of three parts: a) women began taking AZT 14 to 34 weeks into their pregnancy and continued to take it throughout the pregnancy; b) during labour, the woman was given intravenous AZT; and c) AZT was given to the baby for six weeks after its birth.
- 3 Cohen's shorthand for vaccines based on stimulating cell-mediated immunity rather than or as well as antibody responses.

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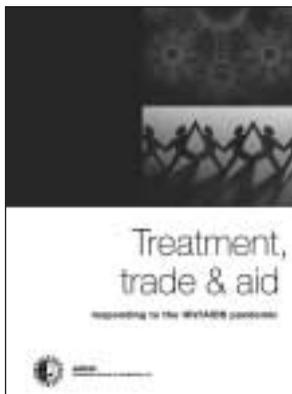
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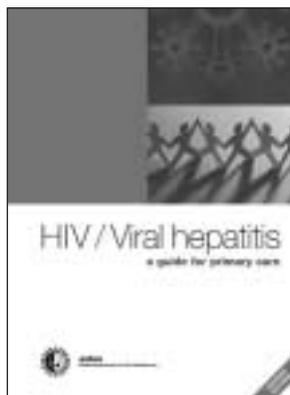
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