



COMMONWEALTH  
DEPARTMENT OF  
HUMAN SERVICES  
AND HEALTH

*Valuing the  
past ...  
investing in  
the future*

Evaluation of the  
National HIV/AIDS Strategy  
1993–94 to 1995–96

AIDS/Communicable Diseases Branch

# Valuing the past ... investing in the future

Evaluation of the  
National HIV/AIDS Strategy  
1993–94 to 1995–96

Professor Richard G A Feachem

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ISBN 0 644 35694 4

First printed September 1995.

Reprinted with amendments November 1995.

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Looking Glass Press  
for Publications and Design (Public Affairs)  
Commonwealth Department of Human Services and Health

Editor Chris Pirie

Cartoons Simon Kneebone

Produced by the Australian Government Publishing Service

A61613 Cat. No. 95 1060 5

# Foreword

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The Commonwealth Minister for Health, the Hon. Dr Carmen Lawrence, appointed me independent evaluator of the National HIV/AIDS Strategy 1993–94 to 1995–96 in December 1994. I was asked to ensure that the evaluation be conducted in a rigorous and fair manner and to present a final report to the Commonwealth Government.

Australia is now 10 years into its HIV/AIDS epidemic. As the period of the second National HIV/AIDS Strategy draws to a close it is timely to take a good hard look at whether the existing programs have achieved the outcomes desired in a cost-effective manner. It is also timely to review whether both the programs and the current level of resourcing are appropriate for the future. For this reason analysis of the available economic, social and epidemiological data was important, and I took a particularly close interest in this aspect of the evaluation.

I visited Australia on several occasions during the course of my appointment and accompanied the evaluation team on an exhaustive round of consultations with groups and individuals from many parts of the country. I commend the team for the openness with which they approached their task. This report was drafted by the evaluation team under my supervision and I consider that appropriate use has been made of all the available evidence. I fully support the report's content and conclusions.

Australia is to be commended for the prompt and creative way in which it has responded to this new and special disease. Two features of this response have been of particular importance and must be maintained: first, non-partisan political support, which has allowed pragmatic and effective programs to operate; second, the partnership, which has harnessed the energies of those groups most affected by HIV, government at several levels, and researchers and health professionals. Australia can be proud of its achievements in controlling the spread of HIV and in developing services to provide care and support for people living with HIV/AIDS. All this has been accomplished at reasonable cost.

There is, however, no room for complacency. With current trends, the target of 2 new infections per 100 000 people per year by the year 2000 will not be achieved. In particular, the unacceptably high rate of new infections among gay men must be confronted, and the emerging epidemic among Aboriginal and Torres Strait Islander people calls for greatly increased effort and resources.

I encourage the Commonwealth Government, and all others who have shared in the work so far, to take up the new challenges presented by HIV/AIDS in Australia and in the region, and I wish them luck in their endeavours.

Professor Richard G A Feachem CBE, BSc, PhD, DSc(Med), Hon FFPHM

# Acknowledgments

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Many people contributed to the production of this report. Thanks to the following:

- all individuals and organisations who made submissions to the evaluation;
- members of the affected communities and their representative organisations, and members of Aboriginal and Torres Strait Islander communities, who talked to Professor Feachem and the evaluation team about their lives and their work to combat HIV/AIDS;
- the individuals who allowed their stories to be told in the evaluation report;
- people who gave their time to participate in consultations and other meetings with members of the evaluation team and Professor Feachem;
- managers and staff of State and Territory health departments who helped the evaluation by answering requests for detailed information and helping with evaluation consultations;
- members of the Schools Network who coordinated a major survey of school-based HIV/AIDS education;
- researchers who provided their data for re-analysis in the social and behavioural consultancies;
- members of the Intergovernmental Committee on AIDS evaluation sub-committee and the evaluation advisory committee and members of the steering committees established to manage particular evaluation projects;
- staff from the AIDS/Communicable Diseases Branch and other parts of the Commonwealth Department of Human Services and Health who helped with the evaluation.

The evaluation team extends additional thanks to those who made important contributions to the writing of the report. Chapter 2 was drafted by John Kaldor and staff at the National Centre in HIV Epidemiology and Clinical Research, with the advice of Sue Kippax, June Crawford, Anthony Smith and Nick Crofts. Chapter 8 was drafted with the assistance of Helen Couper (Department of Human Services and Health) and Helen Watchirs (Commonwealth Attorney-General's Department) and was reviewed by Chris Puplick (Anti-Discrimination Board of New South Wales). Dean Browne, Pam Rhodes and Chris Roberts helped with tables. The vignettes were written by Kay McNiece.

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# Overview

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## THE EVALUATION

The National HIV/AIDS Strategy 1993–94 to 1995–96 is Australia's second National HIV/AIDS Strategy. The first Strategy operated from 1989 to 1993 and was evaluated in 1992. This current evaluation report was requested by Federal Cabinet when it agreed to the National HIV/AIDS Strategy 1993–94 to 1995–96. The Minister for Human Services and Health, the Hon. Dr Carmen Lawrence appointed Professor Richard Feachem independent evaluator. The evaluation was conducted by staff from the Surveillance and Evaluation Unit in the AIDS/Communicable Diseases Branch of the Department of Human Services and Health.

In brief, the terms of reference required the evaluation to assess the effectiveness, efficiency and appropriateness of the Strategy and thereby inform the next phase of national HIV/AIDS policy development.

The evaluation commissioned an economic assessment of aspects of the Strategy, a study of change in behaviour connected with the transmission of HIV, and some additional studies to augment the existing epidemiological data. The evaluation team consulted a broad range of people from all over Australia. The views expressed and those put forward in the 78 submissions made to the evaluation have been carefully assessed and are referred to frequently in the report. An evaluation advisory committee also made an important contribution to the evaluation.

## THE PROBLEM

HIV/AIDS is a new disease and, despite enormous advances in knowledge in the past decade, it is still inadequately understood. There is no cure and there is no vaccine, and these will probably elude us for some time. The best estimate of the total number of people who had acquired HIV infection in Australia by the end of 1994 is 16 000. Among the 5737 people who had progressed to AIDS by the end of 1994, there had been 4014 deaths. HIV/AIDS is an enormous public health problem by any measure.

HIV/AIDS has similarities with other infections in terms of its routes of transmission and modes of treatment and care. It remains exceptional, though, because it presents a unique combination of characteristics: it is 100 per cent fatal (as far as we know); there is a long incubation period, during which an

HIV-positive person may be unaware of his or her infection; there is often a long period between infection and death, during which an HIV-positive person shows no sign of ill health and is able to transmit the infection; there is no cure; and the major modes of transmission involve intimate and sometimes illegal behaviour, making prevention efforts difficult and community reaction to the disease complex. Added to this is the fact that Australia is part of a region with rapidly growing HIV epidemics. The quite proper thrust of public health policy towards 'mainstreaming' HIV/AIDS must be balanced against the reality of the distinct challenges that HIV/AIDS poses to Australian society.

The HIV/AIDS epidemic in Australia is best understood as a number of separate epidemics each having their own trajectories. Public health policy needs to reflect these differences. And, although Australia has one of the best HIV surveillance systems in the world, the closer we come to the present the more difficult it is to accurately estimate the current rate and pattern of new infections. The assessment in this overview is based on the data in Chapter 2 but takes an additional step, based on judgment, in order to inform future HIV/AIDS policy making.

### **The epidemics contained**

Australia has been successful in containing epidemics among injecting drug users, sex workers and heterosexuals but there is still much to be done.

#### **Injecting drug users**

The evidence presented in this report shows that Australia has been successful in preventing a major epidemic of HIV among people who inject drugs. This is a remarkable achievement, in terms of the prevention of human suffering and in economic terms. The seroprevalence of HIV in this population is most probably below 5 per cent, although it is higher among males who also describe themselves as homosexual or bisexual.

The history of very rapid epidemics among people who inject drugs in other parts of the world means, however, that there is no room for complacency.

Needle and syringe exchange programs were established before the first Strategy and have continued in the second Strategy. A study of the cost-effectiveness of these programs suggests that they prevented approximately 3000 infections in 1991 and saved over \$250 million through the avoidance of treatment costs associated with those infections. Needle and syringe exchange programs must be a foundation of Australia's prevention efforts in a third Strategy and beyond. Peer education and community development are important adjuncts to the provision of needles and syringes and should also be integral to the long-term response.

These public health measures, which benefit the whole Australian population,

must be given maximum support through whatever legislative action is necessary. A key development in the second Strategy, which should be carried further in a third Strategy, is recognition of the role of these education and prevention programs and legislative measures in preventing transmission of other blood-borne pathogens such as hepatitis C.

Since nearly half of all people imprisoned in Australia report a history of injecting drugs, and about half of these people continue to inject while in prison, it is vital that more efforts are made to overcome barriers to the provision of safe injecting equipment in Australian prisons. This would also help reduce the currently high rates of hepatitis C transmission resulting from the sharing of contaminated injecting equipment in prisons. HIV prevention efforts in prisons would also be helped if condoms were provided. Prisons are of central importance in HIV prevention among Australia's indigenous people because of the over-representation of these people in prison populations.

### **Sex workers**

In some parts of the world, notably southern Asia and sub-Saharan Africa, female sex workers have been documented as having a high prevalence of HIV infection. In contrast, HIV prevalence among female sex workers in the sex industry in Australia has been very low, as has been the prevalence of sexually transmitted diseases (such as gonorrhoea, syphilis and chlamydia). Condom use is reported to be very high in the organised sex industry: this is the result of vigorous peer education by sex workers themselves, supported by government programs. Laws relating to prostitution should be reformed to increase the safety of sex workers in all parts of the industry. Sex workers who are illegal immigrants, especially from countries with a high prevalence of HIV, and men with a history of sex work require greater attention in a third Strategy; otherwise, HIV prevalence rates could rise rapidly among these communities and their clients.

### **Heterosexuals**

Although HIV has been transmitted heterosexually from men to women and from women to men in Australia, this mode of transmission remains rare. Among the sources of data for this conclusion are the mandatory HIV antibody testing of blood donors and Defence Force entrants.

The rate of heterosexual HIV transmission has, however, been rising in the last decade. The number of new HIV diagnoses in women who became infected through heterosexual contact is increasing. These trends must be closely monitored as part of the overall surveillance strategy.

Heterosexual transmission among Aboriginal and Torres Strait Islander people is also a concern. Although sex between men is currently the predominant mode of HIV transmission, the cumulative proportion of HIV notifications attributed to heterosexual contact among Aboriginal and Torres Strait Islander

people (24 per cent) is significantly higher than in the non-indigenous HIV-infected population (7 per cent), and half the cases have been reported since 1992. The epidemic of HIV among Aboriginal and Torres Strait Islander people is discussed below, under the heading 'The epidemic emerging'.

### **The epidemic continuing**

Sex between men has been the principal mode of HIV transmission in Australia since the beginning of the epidemic, and it remains so. By the end of 1994, 90 per cent of cumulative AIDS cases in adults among persons whose exposure category was known had occurred in men with a history of homosexual contact. During 1994, 85 per cent of newly diagnosed HIV infections, and 88 per cent of newly acquired HIV infections, among persons whose exposure category could be determined were in men with a history of homosexual contact.

Although the proportion of new diagnoses of HIV and AIDS occurring in homosexually active men has remained high, there has been a considerable fall in the absolute number of new HIV diagnoses in this group, from a peak of 2284 in 1987 to 772 in 1994. Using the statistical method of back projection, it is estimated that new infections (as distinct from new diagnoses) for the Australian population as a whole have levelled out at approximately 480 per year. The large majority of these are among homosexually active men. The second Strategy set a target of reducing the rate of transmission to 2 per 100 000 people by the year 2000. The current transmission rate appears to have stabilised at about 2.7 new infections per 100 000 people per year. The national target will not be reached unless there are substantial advances in reducing the epidemic among homosexually active men.

During the evaluation a number of parties expressed fear that a second wave of HIV infection had begun among homosexually active men. The data do not support this, but, as noted, the data are less accurate the closer we come to the present. What we can know with some confidence is that the incidence of HIV among this group has barely declined in the last three to four years. There are probably many reasons for this 'plateau', among them complacency arising from a perception that the crisis had past, 'burnout' among gay men and those involved in HIV/AIDS education due to the death of lovers and friends and the decimation of social networks, and difficulties sustaining safe sexual practices over a long period. Whatever the cause, the plateau is not satisfactory.

The Commonwealth and State and Territory governments, the Australian Federation of AIDS Organisations, the State and Territory AIDS councils, the affected communities, and all those involved in the education of homosexually active men must pursue more effective education strategies. Hard questions should be asked about the approaches used to date and a more critical culture of evaluation should be encouraged. As part of this reappraisal,

epidemiological, social and behavioural research must be pursued to help redefine the problem and evaluate solutions.

### **The epidemic emerging**

As of mid-1995, there is almost certainly an epidemic of HIV in its early stages among Aboriginal and Torres Strait Islander communities. It probably began in the 1990s and is only just starting to be detected by the surveillance system.

As noted, new HIV diagnoses in Australia between 1992 and 1994 constituted only 17 per cent of all cases of HIV ever notified, whereas among Aboriginal and Torres Strait Islander people they constituted 50 per cent of all cases of HIV ever notified for this group. Although the numbers involved are small at this stage, the extent of the problem is most probably being under-reported.

Some hope can be gained from the data from voluntary antenatal testing of pregnant women and from the testing of a proportion of prison entrants in all States and Territories. These indirect sources continue to show low HIV prevalence among Aboriginal and Torres Strait Islander people. As well, the increase in new diagnoses may also be a result of better testing and contact tracing in recent years. But weighed against this are the continuing high rates of sexually transmitted diseases among Aboriginal and Torres Strait Islander people. The presence of STDs can facilitate the transmission of HIV; it is also a marker of the high-risk behaviour that is associated with the transmission of HIV. STDs constitute an important public health problem in their own right, and lack of success in reducing the size of this problem among Aboriginal and Torres Strait Islander people bodes ill for the successful control of HIV.

The policy response to this emerging epidemic should have five aspects. First, work must proceed in close partnership with Aboriginal and Torres Strait Islander communities and in full recognition of their multiple health and social disadvantages. Better links must be made between HIV/AIDS/STD initiatives, existing health services, and the new Office for Aboriginal and Torres Strait Islander Health Services in the Commonwealth Department of Human Services and Health. Increased efforts should be made in a way that enhances Aboriginal and Torres Strait Islander ownership of the problem. Recognition of the diversity of Aboriginal and Torres Strait Islander peoples must be one of the starting points in all aspects of the response.

Second, education and prevention funds for Aboriginal and Torres Strait Islander people through the Special Funding Program and the Matched Funding Program should be increased. The level of funds for Aboriginal and Torres Strait Islander programs has increased in the second Strategy but there is no indication from the data on STDs that the current effort corresponds with the size of the problem.

Third, better social, behavioural and epidemiological data are required in order to accurately define and describe the problem. There appears to be a growing

willingness among Aboriginal and Torres Strait Islander people to accept data collection as part of an integrated public health response to HIV and STDs. Questions of ownership and control are particularly sensitive in relation to the collection and use of data, but they must be resolved.

Fourth, better evaluation of projects and programs is required, so that knowledge of what approaches work best can be developed over time. Since 1989 over \$15 million of HIV/AIDS program funds have been spent on HIV/AIDS/STD programs directed at Aboriginal and Torres Strait Islander communities and much of this has gone into small localised responses. But information about the successes achieved or the lessons learnt is scant. The Commonwealth and State and Territory governments, along with Aboriginal medical services and Aboriginal and Torres Strait Islander communities, should aim to have a much greater understanding of the effectiveness of education and prevention programs in five years' time. The project and program evaluations should be closely linked with better data collection.

Fifth, there must be increased medical preparedness to deal with the epidemic. The Intergovernmental Committee on AIDS, in consultation with other relevant bodies, should develop an action plan to ensure that the necessary health service infrastructure exists. This should include the development of appropriate HIV/AIDS treatment protocols and training for health care workers. Community-based care must be enhanced through measures to develop greater acceptance of HIV-positive Aboriginal and Torres Strait Islander people across all health services, but especially within their own communities.

## **IS A NATIONAL HIV/AIDS STRATEGY STILL NECESSARY?**

The four programs of the Strategy each have their own achievements and their own reasons for reform and continuation.

### **The Education and Prevention Program**

HIV infection costs the Australian community dearly, in human and financial terms. The cost of providing treatment and care in 1992–93 was \$130 million. In the same year the total indirect cost from earnings lost because of illness caused by HIV/AIDS and premature death from AIDS was \$313 million.

Although it is not possible to establish direct causal links between the Education and Prevention Program and a reduction in HIV transmission, the evidence presented in this evaluation strongly supports the contention that the Program has been both effective and efficient in reducing the amount of high-risk behaviour and reducing the transmission of HIV in Australia. Overall, when the prevention of an epidemic among people who inject drugs is combined with large achievements in controlling the epidemic among

homosexually active men, the Education and Prevention Program has been a very good public health investment.

HIV/AIDS remains a serious public health problem and education and prevention approaches are the sole defence. There is no case for a reduction in effort, but a strong case for refocussing effort on where the epidemic is most severe and most likely to increase. HIV/AIDS education and prevention have contributed to the control of other diseases—hepatitis C and STDs particularly—and these wider benefits should continue to be sought out, to maximise the public health benefit from each dollar spent.

### **The Treatment and Care Program**

The Treatment and Care Program has facilitated the delivery of services of reasonable quality to people living with AIDS in areas where the prevalence of AIDS is highest. Problems with access remain for those outside large urban areas and for groups that systematically endure poor access to health services. The changing pattern of disease among people living with AIDS suggests that prophylaxis for diseases such as PCP (*Pneumocystis carinii* pneumonia) is working. The provision of inpatient hospital services is a State and Territory responsibility that is being adequately managed. If it were not for the very unequal distribution of AIDS patients across the States and Territories, absorption of the Medicare Hospital Funding Grants for AIDS into the general Medicare agreements would seem sensible.

The lifetime cost of treating a person with HIV was around \$93 000 in 1992–93. The largest part of the health care costs is incurred in the last few months of life and stems mainly from the cost of hospitalisation, so there are economic as well as humanitarian reasons for developing effective community care networks that can reduce the need for hospital admission.

But care in the community requires more support. Volunteer services must be given close attention by State and Territory governments. An enhanced role for appropriately skilled general practitioners would allow for wider availability of community care. Action must be taken to meet the growing need for services in areas such as ‘step-down’, or intermediate care, mental health, and dental health.

The list of unmet needs is almost limitless and the resources available are finite. The Commonwealth must, therefore, be clearer about what it expects the State and Territory governments to provide by way of a ‘continuum of care’ through the Treatment and Care Program, and State and Territory governments must demonstrate an improved capacity to plan, deliver and account for the services they provide.

The frustration people living with HIV/AIDS and their doctors express about problems with financing and gaining access to new drugs must be listened to

and acted on by Commonwealth, State and Territory government agencies with responsibilities in this area. The number of new HIV/AIDS treatments is expected to increase in the next few years, and this frustration will grow if administrative arrangements are not improved between the Commonwealth and State and Territory governments.

### **The Research Program**

High-quality research from all disciplines has underpinned the National HIV/AIDS Strategy. There are many examples of important contributions made by Australian research to knowledge about HIV/AIDS and ways of combating it. Research will continue to be essential, to enable identification of high-risk behaviours and priority groups, development of best practice models of cost-effective service delivery, and measurement of the outcomes of education and prevention programs. The Research Program will need to encompass some other communicable diseases and sexual health but this should not be done at the expense of ensuring an improved capacity to monitor the epidemic in social, behavioural and epidemiological terms. The transfer of HIV/AIDS research to the National Health and Medical Research Council should occur only if this capacity will not be compromised. The unique role of the three National Centres in HIV Research in relating closely to public health policy must be acknowledged as an achievement worth preserving.

### **The International Assistance and Cooperation Program**

The international component of the National HIV/AIDS Strategy will take on increasing significance as the regional epidemics grow. Apart from concern about the potential for effects on Australia, there are strong humanitarian reasons for Australia continuing to develop a regional response. Australia has been playing a valuable part in global efforts to combat AIDS and this needs to continue. A more coherent strategic framework for cooperation between and coordination of the three Commonwealth government agencies involved and the non-government sector should be developed to maximise effort in the region.

### **The National HIV/AIDS Strategy**

The National HIV/AIDS Strategy is more than the sum of its parts. It provides an agreed national framework of principles, goals, objectives, and roles and responsibilities that guide action by all levels and sectors of government and the affected community. It provides a point of reference for debate and advocacy. Another achievement of the Strategy has been to advance the acceptance of new approaches to public health.

Implementation of the Strategy has been helped by legal reform. There is a continuing need to implement the unfinished HIV/AIDS legal reform agenda—for example, access to needles and syringes in prisons and reform of laws

relating to prostitution—and to consider the broad social and legal reform agenda, including such matters as Aboriginal and Torres Strait Islander people's access to justice. A body should be established to consider legal reform matters associated with HIV/AIDS and other communicable diseases.

The Australian National Council on AIDS is a central component in the Strategy. It provides the Commonwealth with an advisory body that offers specialist expertise whilst being broadly representative. It should be retained and strengthened and its mandate should be revised to enable it to deal with aspects of public health that are wider than HIV/AIDS but that must be dealt with by a body such as the Australian National Council on AIDS in order to ensure an effective response to HIV/AIDS.

The Intergovernmental Committee on AIDS has provided the Commonwealth and State and Territory governments with a mechanism to implement the Strategy. It is timely for its terms of reference to be reviewed in light of new aspects of communicable diseases requiring Commonwealth, State and Territory cooperation and coordination.

Australia's success in its approach to HIV/AIDS has been founded on a supportive, non-partisan approach by the Commonwealth Parliament. This will be equally important for success in the future. Political leaders at the Commonwealth and State and Territory levels should take renewed steps to ensure that the success of the Strategy is acknowledged and that HIV/AIDS continues to be managed in a pragmatic way within a public health framework.

Equally important is the partnership approach that has characterised the Strategy. There are no short cuts to a comprehensive policy framework that involves the affected communities, brings the out the best in all levels of government, and ensures high-quality professional participation. Maintaining the partnership involves constant hard work by all participants, but it is an achievement worth preserving.

The second Strategy made good progress in reducing the rate of transmission of HIV and the personal and social impacts of the infection. Australia should be proud of this. At a cost to the Commonwealth of approximately \$300 million over three years, the second Strategy should be regarded, on the whole, as an efficient use of public health resources. It is important to realise, however, that unless a concerted effort is made in a third Strategy to confront the continuing HIV epidemic among homosexually active men and the emerging HIV epidemic among Aboriginal and Torres Strait Islander people the gains and investment made to date may be lost.

The goals of the National HIV/AIDS Strategy are still clear and valid. The national target transmission rate of 2 new HIV infections per 100 000 people per year by the year 2000 should, however, be reconsidered in light of the several distinct HIV epidemics that require urgent attention.

The first and second Strategies have provided a framework in which to implement a cohesive national response to the HIV epidemic. This evaluation provides strong evidence to support the need for a third Strategy. The three-year length of the second Strategy is too short for a third Strategy: five years would allow for a sustained effort before the next comprehensive evaluation. A national policy framework should be developed during this time to enable the problems caused by HIV/AIDS to be dealt with while relating HIV/AIDS policies and organisational arrangements more closely to those developing in the areas of sexual health and communicable diseases more generally.

# Recommendations

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## **Recommendation 1**

It is recommended that homosexually active men remain the highest priority for the Education and Prevention Program and that program monitoring and accountability arrangements take account of the need to monitor program implementation in relation to stated priorities.

## **Recommendation 2**

It is recommended that the Commonwealth, the State and Territory governments and the Australian Federation of AIDS Organisations and AIDS councils reassess and refocus education and prevention measures for homosexually active men, to further decrease the practice of unprotected anal intercourse and thus decrease the rate of HIV.

## **Recommendation 3**

It is recommended that injecting drug users remain a priority for the Education and Prevention Program. Community development and peer education for injecting drug users should be strengthened.

## **Recommendation 4**

It is recommended that the Commonwealth, the Intergovernmental Committee on AIDS and the Australian National Council on AIDS continue to support intensive education and prevention activities among Aboriginal and Torres Strait Islander communities. These activities should be placed within the broader sexual health and injecting drug use contexts and use models of best practice.

## **Recommendation 5**

It is recommended that the Commonwealth, the States and Territories, and non-government organisations support the very important role of people living with HIV/AIDS in education and prevention strategies.

## **Recommendation 6**

It is recommended that individual States and Territories and the Intergovernmental Committee on AIDS work with the departments responsible

for corrective services to ensure that in prisons there is continued emphasis on the implementation of education and prevention strategies that have been shown to be effective in the general community.

### **Recommendation 7**

It is recommended that the Commonwealth and the States and Territories maintain current funding for education and prevention activities directed at sex workers and their clients.

### **Recommendation 8**

It is recommended that the Commonwealth and the States and Territories continue to fund training for health care workers (including indigenous health care workers) and peer educators. The trend for education of health care workers to be mainstreamed should continue.

### **Recommendation 9**

It is recommended that the Commonwealth and the States and Territories continue to provide education to the general community but that the funding level be decreased.

### **Recommendation 10**

It is recommended that school-based education, in a broader sexual health context, remain a primary approach to education for youth and that it be adequately funded.

### **Recommendation 11**

It is recommended that the Commonwealth and the States and Territories clarify the definitions of 'mainstreaming' and 'broader sexual health context' and assist the integration of HIV/AIDS into mainstream programs where this is appropriate. This integration must be supported by a clear understanding of roles and responsibilities and adequate staff training.

### **Recommendation 12**

It is recommended that HIV education and prevention continue to be incorporated in broader communicable disease approaches at the Commonwealth and State and Territory levels. Accountability mechanisms should exist to ensure that our response to HIV/AIDS is not compromised.

### **Recommendation 13**

It is recommended that the Commonwealth, in consultation with the Intergovernmental Committee on AIDS, initiate an independent evaluation of

peer education and community development projects, with a view to developing best practice models.

#### **Recommendation 14**

It is recommended that the Commonwealth ensure that revision and dissemination of changed educational messages about safe practices occurs in a coordinated and timely fashion.

#### **Recommendation 15**

It is recommended that State and Territory treatment and care plans ensure the continuing viability of community-based volunteer services and pay closer attention to the needs of carers.

#### **Recommendation 16**

It is recommended that health maintenance and monitoring be included in a third National HIV/AIDS Strategy and in State and Territory treatment and care plans.

#### **Recommendation 17**

It is recommended that the Australian National Council on AIDS and the Intergovernmental Committee on AIDS review current arrangements for pre- and post-HIV test counselling and identify sustainable, long-term measures to ensure that service providers are trained to undertake risk-factor assessment and counsel patients in an appropriate manner. This should be combined with work to improve testing procedures for all blood-borne pathogens.

#### **Recommendation 18**

It is recommended that the existing HIV testing policy framework be maintained, that the Intergovernmental Committee on AIDS continue to explore ways of reducing demand for testing in low-risk populations, and that the Commonwealth closely monitor the overall impact of an increase in testing on the Matched Funding Program.

#### **Recommendation 19**

It is recommended that the Intergovernmental Committee on AIDS review variations in accreditation practices relevant to prescribing Highly Specialised Drugs Scheme treatments with a view to providing that principles of equity and access are maintained while providing a high standard of service delivery.

**Recommendation 20**

It is recommended that the Commonwealth take responsibility for reviewing barriers to general practitioners' involvement in HIV medicine and include measures to overcome these in a third Strategy.

**Recommendation 21**

It is recommended that State and Territory governments give consideration to the need for intermediate care in the development of their treatment and care plans.

**Recommendation 22**

It is recommended that State and Territory governments include mental health services as an integral part of their treatment and care plans. The Intergovernmental Committee on AIDS should undertake a needs assessment and identify possible solutions applicable to AIDS-related dementia.

**Recommendation 23**

It is recommended that a third National HIV/AIDS Strategy specifically acknowledge the importance of dental care in treatment protocols for people with HIV/AIDS. State and Territory treatment and care plans should include an assessment of the adequacy of dental health care for people living with HIV/AIDS.

**Recommendation 24**

It is recommended that the Australian National Council on AIDS ensure that the proposals resulting from the reviews of implementation of the Baume report, the approvals process and the listing of pharmaceuticals under s. 100 of the *National Health Act 1953* be examined and, as appropriate, implemented as a matter of urgency.

**Recommendation 25**

It is recommended that the Commonwealth, the States and Territories, and non-government organisations support the role of people living with HIV/AIDS in treatment and care.

**Recommendation 26**

It is recommended that, as part of the development of State and Territory treatment and care plans, the capacity of the system to deliver a continuum of care be considered and the development of case management strategies be explored.

**Recommendation 27**

It is recommended that the Intergovernmental Committee on AIDS, in consultation with the Office for Aboriginal and Torres Strait Islander Health Services and the Australian National Council on AIDS Working Group on Aboriginal and Torres Strait Islander Sexual Health, develop an Aboriginal and Torres Strait Islander HIV/AIDS and Tuberculosis Medical Preparedness Action Plan.

**Recommendation 28**

It is recommended that a third National HIV/AIDS Strategy increase funds for HIV/AIDS/STD initiatives directed at Aboriginal and Torres Strait Islander people. If necessary, the increase in resources should be gradual to allow adequate time for consultation and planning.

**Recommendation 29**

It is recommended that the Commonwealth revise the guidelines for the Special Funding Program. The new guidelines should explicitly require, as a condition of funding, that State and Territory governments consult with Aboriginal and Torres Strait Islander communities and develop comprehensive strategic plans for the use of funds. The plans should take account of the need to improve the collection of surveillance data and identify how data will be collected, analysed and used in partnership with Aboriginal and Torres Strait Islander health services.

**Recommendation 30**

It is recommended that State and Territory treatment and care plans include an assessment of HIV-positive women's needs for peer support and their specialised health and social needs.

**Recommendation 31**

It is recommended that the Australian National Council on AIDS take responsibility for ensuring that matters relating to the widespread use of complementary therapies by people living with HIV/AIDS are adequately and appropriately examined and resolved.

**Recommendation 32**

It is recommended that the Commonwealth develop, as a matter of urgency, Casemix payment systems that include care in the community and that require minimum standards of care to be met.

**Recommendation 33**

It is recommended that the Commonwealth Government and the Intergovernmental Committee on AIDS consider the report of the National Health and Medical Research Council's Tuberculosis Working Party as soon as it is available and implement its recommendations as appropriate. Tuberculosis monitoring and treatment should be incorporated in the Intergovernmental Committee on AIDS action plan to ensure medical preparedness for an epidemic of HIV/AIDS and tuberculosis among Aboriginal and Torres Strait Islander people. The Commonwealth should improve monitoring and surveillance of HIV/TB co-infection.

**Recommendation 34**

It is recommended that Australian National Council on AIDS commission the Clinical Trials and Treatments Advisory Committee to review the current stage of development of clinical protocols in HIV/AIDS medicine, to report on those areas where the development of protocols is feasible and worth pursuing, and to propose a method of implementation.

**Recommendation 35**

It is recommended that, as part of the process of monitoring the implementation of a third National HIV/AIDS Strategy, the Commonwealth require State and Territory governments to have developed comprehensive treatment and care plans based on the concept of a continuum of care as a condition for the receipt of funding.

**Recommendation 36**

It is recommended that the Intergovernmental Committee on AIDS introduce a national survey of service use and costs in the treatment of people living with HIV/AIDS, combined with measures of the quality of life for patients.

**Recommendation 37**

It is recommended that the Intergovernmental Committee on AIDS and the Australian National Council on AIDS agree on a set of principles that can be used to guide mainstreaming of HIV/AIDS treatment and care activities during the course of a third National HIV/AIDS Strategy. They should also agree on a set of outcome measures that can be used to monitor performance in this regard.

**Recommendation 38**

It is recommended that Treatment and Care Program funding for community-based service provision through the Matched Funding Program and the Special

Funding Program be maintained in a third Strategy. Other avenues for recognising financially the uneven distribution of AIDS cases should be explored by the Commonwealth Department of Human Services and Health through the Commonwealth Grants Commission. When this has been resolved, the dedicated Medicare Hospital Funding Grants for AIDS should be incorporated in the general Medicare funding arrangements.

### **Recommendation 39**

It is recommended that in a third National HIV/AIDS Strategy the Commonwealth alter the objective of the Research Program to say that research results should be translated into practice where appropriate.

### **Recommendation 40**

It is recommended that the Commonwealth AIDS Research Grants Committee review the responsibilities that are placed on researchers either through project grants or the National Centres in HIV Research with a view to maximising the use of research and developing more effective ways of ensuring that researchers meet their responsibilities. The Committee should work with the National Centres to develop performance indicators to monitor progress towards these objectives.

### **Recommendation 41**

It is recommended that, in examining the training needs of HIV/AIDS educators at a national level, the AIDS/Communicable Diseases Branch of the Department of Human Services and Health consider the need for educators to develop skills in using research, the need to foster a culture of 'evidence-based' program development among educators, and the need for educators to become partners with professional researchers in the education research process.

### **Recommendation 42**

It is recommended that the National Health and Medical Research Council take steps to foster high-quality social science health research, including ensuring sufficient representation of social scientists on relevant committees and in review processes.

### **Recommendation 43**

It is recommended that, in consultation with the Australian National Council on AIDS, the National Health and Medical Research Council consider redefining the scope of 'ring-fenced' HIV/AIDS research funds to include the broader areas of sexual health and communicable diseases.

**Recommendation 44**

It is recommended that, in negotiating the transfer of HIV/AIDS research funds for project grants and training awards to the National Health and Medical Research Council, the Australian National Council on AIDS ensure the continued 'ring-fencing' of HIV/AIDS research funds until such time as this arrangement is made redundant by the increased quality and quantity of research applications and by the capacity of the National Health and Medical Research Council to foster appropriate research in this area. It is reasonable to expect this to occur over a 10-year period.

**Recommendation 45**

It is recommended that, as part of a third National HIV/AIDS Strategy, the Australian National Council on AIDS review the Commonwealth AIDS Research Grants Committee's terms of reference and endorse its role in overseeing the work of the three National Centres in HIV Research.

**Recommendation 46**

It is recommended that the administration of the National Centre in HIV Social Research and the National Centre in HIV Epidemiology and Clinical Research be located within the AIDS/Communicable Diseases Branch of the Department of Human Services and Health for the duration of the current agreements. In the longer term their administrative arrangements should match their purpose as instruments of public health policy and practice.

**Recommendation 47**

It is recommended that funding for aspects of the Research Program related to the operation of the National HIV Reference Laboratory and for enabling the Department of Human Services and Health to respond quickly to emerging public health problems in communicable diseases be incorporated in funding for a third National HIV/AIDS Strategy.

**Recommendation 48**

It is recommended that Australia continue to play an active role in international policy development and implementation through participation in United Nations and other international forums and activities.

**Recommendation 49**

It is recommended that Australia continue to focus its international assistance effort on the Asia-Pacific region.

**Recommendation 50**

It is recommended that a third National HIV/AIDS Strategy better acknowledge the diversity of players, activities and funding sources that contribute to the International Assistance and Cooperation Program.

**Recommendation 51**

It is recommended that an interdepartmental committee comprising representatives of the Department of Human Services and Health, AusAID and the Department of Foreign Affairs and Trade be established to provide leadership and coordination for the International Assistance and Cooperation Program.

**Recommendation 52**

It is recommended that the proposed interdepartmental committee develop a work plan that takes a more strategic approach to Australia's International Assistance and Cooperation Program and clarifies specific objectives and priorities.

**Recommendation 53**

It is recommended that the proposed interdepartmental committee develop a set of best practice guidelines for the International Assistance and Cooperation Program.

**Recommendation 54**

It is recommended that a third National HIV/AIDS Strategy emphasise the importance of impact and outcome evaluations of International Assistance and Cooperation Program activities. A mechanism for the dissemination of evaluation findings should be established.

**Recommendation 55**

It is recommended that a third National HIV/AIDS Strategy recognise the importance of research that is relevant to the International Assistance and Cooperation Program.

**Recommendation 56**

It is recommended that the Commonwealth Attorney's-General Department enhance its capacity to respond to legal problems presented by HIV/AIDS.

**Recommendation 57**

It is recommended that the Commonwealth Attorney-General's Department and the Commonwealth Department of Human Services and Health encourage all jurisdictions to establish bodies to implement the Legal Working Party's recommendations.

**Recommendation 58**

It is recommended that the Commonwealth Attorney-General's Department review the effectiveness of the Implementation Working Group and make recommendations on the roles, responsibilities and resourcing of a national, intersectoral body to consider continuing legal reform questions associated with HIV/AIDS and other communicable diseases.

**Recommendation 59**

It is recommended that the Implementation Working Group give consideration to measures needed to facilitate the appropriate mix of specialist and generalist advice available through community legal centres and private legal practices.

**Recommendation 60**

It is recommended that anti-discrimination education for the general community and health care workers remain a priority for education and prevention.

**Recommendation 61**

It is recommended that the Human Rights and Equal Opportunity Commission and State and Territory bodies that deal with formal discrimination complaints improve their mechanisms for hastening the consideration of complaints by people with life-threatening illnesses and for undertaking class actions.

**Recommendation 62**

It is recommended that a third National HIV/AIDS Strategy endorse the continuing need for a partnership approach to the epidemic.

**Recommendation 63**

It is recommended that the Commonwealth give maximum support to the development of a partnership with Australia's indigenous people through the Australian National Council on AIDS Working Party on Aboriginal and Torres Strait Islander Sexual Health.

**Recommendation 64**

It is recommended that the Commonwealth strengthen its requirement that State and Territory governments develop strategic plans for the use of Special Funding Program funds in partnership with Aboriginal and Torres Strait Islander people. The Commonwealth should ensure adequate links with broader participation mechanisms established through the Office for Aboriginal and Torres Strait Islander Health Services.

**Recommendation 65**

It is recommended the Commonwealth continue to move away from direct service delivery and assume a stronger role in strategic planning, coordination, leadership and monitoring of outcomes achieved through the Strategy.

**Recommendation 66**

It is recommended that State and Territory governments continue to have prime responsibility for program administration and coordination of service delivery within their jurisdictions. They should ensure that services are responsive to local needs.

**Recommendation 67**

It is recommended that State and Territory governments ensure that community-based organisations they fund have adequate links with priority groups, are responsive to their clients, and are the most appropriate organisations to deliver specific services.

**Recommendation 68**

It is recommended that the Intergovernmental Committee on AIDS coordinate the development of performance measures, including outcome indicators and program monitoring tools, as a priority.

**Recommendation 69**

It is recommended that a single, national education sub-committee of the Australian National Council on AIDS be formed for strategic planning and coordination of education and prevention programs. This sub-committee should have representation from all relevant organisations.

**Recommendation 70**

It is recommended that during a third Strategy the Commonwealth and the States and Territories review the role of Intergovernmental Committee on AIDS and its relationship with other national communicable diseases committees. It should be reconstituted as a body with broader terms of reference and broader representation as appropriate.

**Recommendation 71**

It is recommended that the role of the Australian National Council on AIDS be endorsed and strengthened in a third Strategy. The Council should be given a mandate to deal with a broader range of matters of relevance to HIV/AIDS and to collaborate with other bodies as appropriate.

**Recommendation 72**

It is recommended that the Commonwealth fund the Australian Federation of AIDS Organisations on the basis of an agreed set of outcomes and an agreed set of performance indicators to monitor those outcomes.

**Recommendation 73**

It is recommended that Commonwealth funding of Haemophilia Foundation Australia be conditional on an agreed set of outcomes and an agreed set of performance indicators to monitor those outcomes.

**Recommendation 74**

It is recommended that the Commonwealth ensure that the Parliamentary Liaison Group continues and is adequately supported. Further, use of the Parliamentary Liaison Group as a vehicle for disseminating information on hepatitis C and other public health problems should be explored.

**Recommendation 75**

It is recommended that the Intergovernmental Committee on AIDS and the Australian Health Ministers Advisory Council propose to the Australian Health Ministers Council that parliamentary liaison groups be established at the State and Territory level as part of the continuing development of a non-partisan approach to HIV/AIDS and other public health matters.

**Recommendation 76**

It is recommended that the Commonwealth, in consultation with all other members of the partnership, develop a third National HIV/AIDS Strategy, which should have a mandate until 2000–01.

**Recommendation 77**

It is recommended during the proposed third National HIV/AIDS Strategy the Commonwealth develop a national policy framework that integrates the essential elements of a successful response to HIV/AIDS with those required for managing problems in the areas of sexual health and communicable diseases.

**Recommendation 78**

It is recommended that the level of funding in a third Strategy be similar to that in the second Strategy and that funds in the order of \$2 million to \$2.5 million be reallocated from the National Education Program to the Special Funding Program for HIV/AIDS and STD services to Aboriginal and Torres Strait Islander people.

**Recommendation 79**

It is recommended that the Commonwealth, in consultation with the States and Territories, review monitoring and accountability mechanisms for a third Strategy, with a view to developing better measures of outputs and outcomes.

# Introduction

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## 1.1 BACKGROUND

In 1993 Federal Cabinet approved the National HIV/AIDS Strategy 1993–94 to 1995–96 and requested that the Strategy be evaluated and reported on by December 1995. This report fulfils that requirement.

A framework for the evaluation was developed by the Surveillance and Evaluation Unit of the AIDS/Communicable Diseases Branch of the Commonwealth Department of Human Services and Health in consultation with the IGCA sub-committee that included representatives from the AFAO and the National Centre in HIV Epidemiology and Clinical Research.

## 1.2 THE TERMS OF REFERENCE

The terms of reference were as follows:

To inform the development of the next phase of Australia's response to the HIV/AIDS epidemic, including its relationship to broader communicable diseases issues, by:

- Determining the effectiveness of the Strategy and its component programs in achieving their objectives and in contributing to progress towards the national target.
- Assessing the success of the implementation of the Strategy and its component programs in terms of coverage and access, quality and efficiency, and compliance with the guiding principles and intended approach of the Strategy.
- Assessing the appropriateness of the Strategy to deal with the HIV/AIDS epidemic in Australia.

## 1.3 THE INDEPENDENT EVALUATOR

To enhance the independence and rigour of the evaluation, the Commonwealth Minister for Health, the Hon. Dr Carmen Lawrence, appointed Professor Richard Feachem as the independent evaluator of the Strategy. Professor Feachem is Dean Emeritus of the London School of Hygiene and Tropical Medicine. He made four visits to Australia for the evaluation. These visits involved participation in the six consultation workshops as well as meetings with the affected communities and a wide range of people involved in providing or planning HIV/AIDS services or programs. Professor Feachem was also

involved in discussion and review of the technical aspects of the evaluation relating to epidemiology, social and behavioural research, and economics.

## 1.4 METHOD

Appendix A describes in detail the method of evaluation.

The evaluation research was guided by a series of questions that were generated by taking each of the terms of reference and applying them to the Strategy's four program areas where appropriate. For example, questions about the effectiveness of each program in meeting its stated objectives (the first term of reference) were developed and a plan was developed for gathering and analysing data necessary to answer the questions.

The questions were used to guide the six consultation workshops held for the evaluation. They were also used to guide individuals and organisations making submissions and in seeking written information to the evaluation from State and Territory governments and the AIDS/Communicable Diseases Branch of the Department of Human Services and Health.

Some of the questions called for technical information and this was made available through consultancies to the evaluation. The reports of the consultancies will be published as five separate technical appendixes to the evaluation, as follows:

- Technical Appendix 1: Epidemiological Report (NCHECR 1995);
- Technical Appendix 2: An Economic Evaluation of Aspects of the National HIV/AIDS Strategies (Hurley & Butler 1995a);
- Technical Appendix 3: An Analysis of Change Over Time in Social and Behavioural Factors Related to the Transmission of HIV Among Men who Have Sex with Men (Crawford et al. 1995);
- Technical Appendix 4: An Analysis of Change Over Time in Social and Behavioural Factors Related to the Transmission of HIV Among Injecting Drug Users and Prisoners (Crofts et al. 1995);
- Technical Appendix 5: An Analysis of Change Over Time in Social and Behavioural Factors Related to the Transmission of HIV Among Sex Workers, Sex Travellers, and the General Community (Smith et al. 1995).

The epidemiological report was prepared by the National Centre in HIV Epidemiology and Clinical Research as part of its core function as a national centre funded through the Research Program of the Strategy.

Some additional studies to complement the existing data collection were also commissioned for the evaluation.

The evaluation framework, a report on the consultations held, and a report on the submissions received will also be published separately from this report. Appendix B lists the submissions received.

A principal source of data for the evaluation was the project register. This is a database that is managed by the AIDS/Communicable Diseases Branch and contains details of all projects that have received funding from the Commonwealth under the Strategy. It includes projects funded and managed by the Commonwealth alone, projects funded jointly with State and Territory governments, and projects funded by the Commonwealth alone but managed by State and Territory governments.

## **1.5 MANAGEMENT OF THE EVALUATION**

Appendix C describes in detail the management of the evaluation.

The evaluation was managed by the AIDS/Communicable Diseases Branch of the Department of Human Services and Health. The Branch was assisted by an advisory committee established by the Intergovernmental Committee on AIDS and chaired by the chairperson of that Committee.

## **1.6 A WORD ON TERMINOLOGY**

Throughout this report the National HIV/AIDS Strategy released by the Commonwealth in August 1989 is referred to as ‘the first Strategy’, the National HIV/AIDS Strategy 1993–94 to 1995–96 is referred to as ‘the second Strategy’, and ‘a third Strategy’ refers to what this report recommends that the Commonwealth establish from July 1996. The primary focus of the evaluation is the second Strategy. There are, however, many elements of the second Strategy that are a continuation of the first Strategy—the goals, objectives and guiding principles remain largely unchanged—so at times it is not possible to clearly separate the effects of the second Strategy from those of the first. The phrase ‘the Strategy’ is used to mean the continuous elements of both the first and second Strategies.

‘HIV’ refers to the human immunodeficiency virus and ‘AIDS’ refers to acquired immune deficiency syndrome. People with HIV can live for a number of years without symptoms of infection. This report refers to ‘HIV’ when the virus is the point of discussion. ‘AIDS’ is used to refer the end stage of HIV disease, and ‘HIV/AIDS’ is used when it is both the virus and its long-term effects that are relevant.

## **1.7 A WORD ON FUNDS ALLOCATED AND FUNDS EXPENDED**

Sometimes this report refers to funds that have been allocated to programs and sometimes to funds that have been expended by programs on services. The financial statement in Chapter 3 describes the allocation that was made as part of the second Strategy and reports expenditure of these funds across 1993–94 and 1994–95. Chapter 4, however, reports on the implementation of the Education and Prevention Program in these two financial years and includes

the expenditure of funds rolled over from the first Strategy. This has been done because serious under-reporting of actual expenditure on education and prevention in 1993–94 would result if only second Strategy allocations were considered.

# The epidemic of HIV and AIDS in Australia

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## 2.1 INTRODUCTION

This chapter reviews the course and impact of the HIV epidemic in Australia; it is based on the best available epidemiological and behavioural data. In comparison with the evaluation of the first National HIV/AIDS Strategy, we are now in a better position to describe the HIV epidemic, largely because of the close relationship between the development of the Australian HIV Surveillance Strategy and the framework for the current evaluation.

There have been notable advances in surveillance for HIV incidence, HIV prevalence among people who inject drugs, HIV infection in children, and advanced manifestations of HIV infection. This evaluation has also provided the opportunity, for the first time, to compile quantitative national assessments of time trends in social and behavioural factors related to HIV infection and of the impact of HIV infection in Aboriginal and Torres Strait Islander people.

Despite our greatly enhanced ability to describe the HIV epidemic and related factors in Australia, we are still limited in our ability to quantify the influence of specific policies and interventions on the epidemic's course in our country. The assessment of effectiveness still depends to a large extent on qualitative information and judgment, combined with the available quantitative information summarised in this chapter.

Unless otherwise specified, the analysis in this chapter is based on cases of HIV infection and AIDS diagnosed before the end of 1994. In general, data for 1995 remain incompletely reported at the time of writing, but they are referred to where appropriate.

A more detailed treatment of the material in this chapter and acknowledgments of its multiple sources will be published separately as a technical appendix to the evaluation.

## 2.2 OVERVIEW OF THE HIV EPIDEMIC

By the end of 1994 there had been reports of 18 725 diagnosed cases of HIV infection, 5737 cases of AIDS, and 4014 deaths following AIDS in Australia. After statistical adjustment for duplicate reporting, the cumulative number of people diagnosed with HIV by the end of 1994 was estimated to be around 14 500.

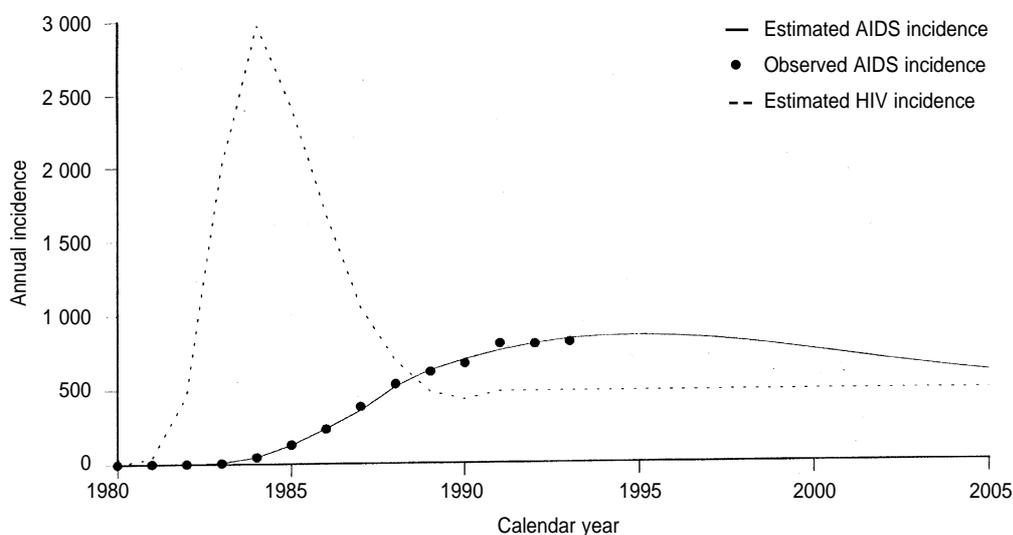
The first cases of AIDS in Australia were reported in 1982–83; they were followed by a rapid increase in the annual number of reported cases. By the late 1980s the rate of increase had begun to slow, as Figure 2.1 shows.

Use of the method of back projection, which is based on knowledge of the rate of progression from HIV infection to AIDS, provides the explanation. There was a peak in the number of new HIV infections in 1984 and then a sharp decline between 1985 and 1990. As a consequence, the number of people progressing to AIDS increased for the 10 years following the peak in HIV transmission but is now approaching a plateau. Figure 2.2 shows that the estimated number of people living with HIV has been declining slightly in New South Wales since 1987, but the number in other States and Territories has been fairly constant.

The back projection method is less useful in estimating the number of new HIV infections occurring in more recent years because few of these cases have yet progressed to AIDS. Estimates of HIV incidence in more recent years have therefore been based on cohort studies of people tested for HIV on multiple occasions over time. These studies provide no evidence of a substantial change in the annual number of new cases of HIV infection in Australia in the recent past.

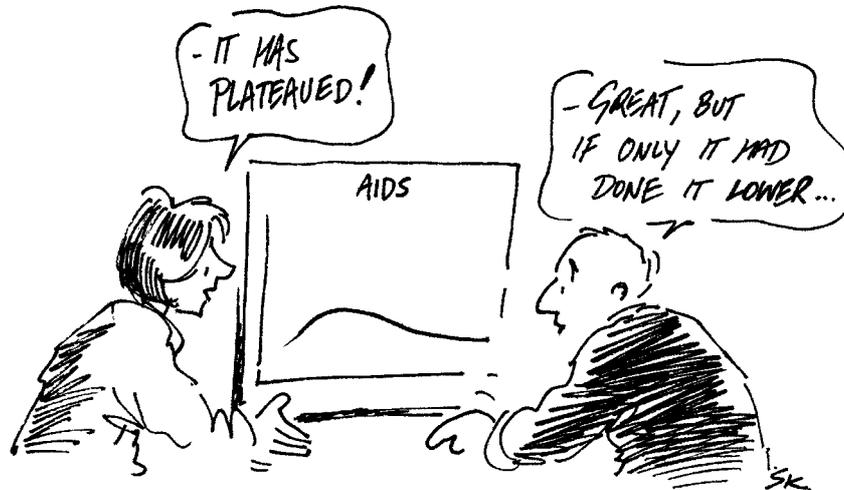
Taken together, the results of back projection and cohort studies suggest that around 480 people in Australia became infected with HIV in 1993. The estimated cumulative number of people who had become infected HIV infection in Australia to the end of 1994 was 16 000, compared with the estimated 14 500 of these people who had been diagnosed with HIV infection.

**Figure 2.1 Observed AIDS incidence to 1993, predicted AIDS incidence to 2005, and estimated HIV incidence to 2005**



Note: Estimated incidence to 2005 assumes HIV incidence is fixed at 480 per year from 1991.

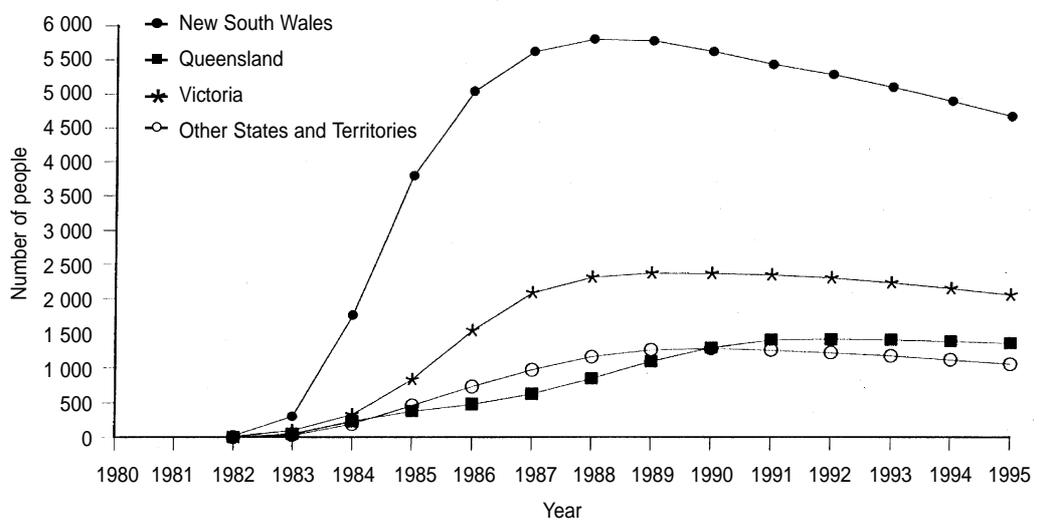
Source: NCHECR (1995).



Assuming that the rates of new HIV infection and progression to AIDS in people with HIV infection have remained constant in the recent past and will continue to do so, the future incidence of AIDS in Australia can be predicted. As Figure 2.1 shows, the annual number of people developing AIDS each year will remain close to the current level for another decade, after which it will begin to decline. If infection rates rise substantially again, the annual number of new AIDS cases would also rise (after a lag of a few years) unless more effective treatments for HIV have by then been developed.

In 1989 national surveillance for AIDS cases was supplemented by national reporting of new HIV diagnoses, and in 1991 new infections became

**Figure 2.2 Estimated number of people living with HIV, by State and Territory, 1980 to 1995**



Source: NCHECR (1995).

reportable as a separate category of the new diagnoses. Epidemiological monitoring of new HIV diagnoses has provided a broader picture of the HIV epidemic in Australia than has surveillance for AIDS cases alone. Although HIV surveillance will not detect cases of HIV infection in people who have not been tested, it does include cases that have not yet progressed to AIDS and infections that are more recently acquired. As the surveillance system for HIV diagnosis has developed there has been a steady decline in the annual number of people reported as newly diagnosed with HIV infection, but a steady increase, to over 200 in 1994, in the sub-group whose infection was found to have been acquired in the past 12 months.

The vast majority of those diagnosed cases of HIV infection and AIDS in Australia for which the route of infection was reported have been in men who became infected through homosexual contact. As Table 2.1 shows, this proportion has remained almost constant during the HIV epidemic in Australia. The numbers of diagnosed cases of HIV infection associated with heterosexual contact, the injection of illicit drugs, or medical procedures have been relatively small compared with the number of cases transmitted through sexual contact between men. The number and proportion of cases for which no exposure category was reported has steadily declined as surveillance procedures have improved nationally. The annual number of HIV diagnoses in women has been roughly constant in the past decade, but there has been a clear move towards a higher number of cases attributed to heterosexual transmission (paralleled by a decline in other modes of transmission). Because of the relatively small number of women who have acquired HIV infection in Australia, the transmission of HIV from mother to child has been rare.

Four cases of occupational transmission of HIV to health care workers have been documented in Australia. There is no evidence of HIV transmission through routes other than sexual contact, blood contact or from mother to child.



**Table 2.1** Number of reported cases of newly diagnosed HIV infection, by sex, year of diagnosis and exposure category, 1993–94

Exposure category	To 1984	1985 to 1987	1988 to 1990	1991 to 1992	1993 to 1994	Cumulative total <sup>a</sup>
<b>Males</b>						
Number with newly diagnosed infection	542	6701	4294	2342	1824	15741
Homosexual/bisexual contact	301 (81.8)	3 717 (87.9)	2 815 (85.8)	1 552 (81.9)	1 331 (81.0)	9 740 (85.1)
Homosexual/bisexual contact and ID use	2 (0.5)	124 (2.9)	92 (2.8)	65 (3.4)	76 (4.6)	360 (3.1)
ID use	0 (0.0)	119 (2.8)	180 (5.5)	87 (4.6)	54 (3.3)	441 (3.9)
Heterosexual contact	3 (0.8)	58 (1.4)	138 (4.2)	164 (8.6)	161 (9.8)	525 (4.6)
Receipt of blood/blood products/tissue	61 (16.6)	209 (4.9)	49 (1.5)	21 (1.2)	16 (1.0)	361 (3.2)
Mother to child	1 (0.3)	2 (0.1)	6 (0.2)	6 (0.3)	5 (0.3)	20 (0.1)
Other/undetermined	174	2 472	1 014	447	181	4 294
<b>Females</b>						
Number with newly diagnosed infection	12	284	263	167	154	881
ID use	0 (0.0)	61 (42.4)	50 (29.4)	22 (17.5)	18 (13.4)	151 (26.2)
Heterosexual contact	1 (50.0)	37 (25.7)	104 (61.2)	90 (71.4)	105 (78.4)	338 (58.6)
Receipt of blood/blood products/tissue	1 (50.0)	43 (29.8)	15 (8.8)	10 (7.9)	2 (1.5)	71 (12.3)
Mother to child	0 (0.0)	3 (2.1)	1 (0.6)	4 (3.2)	9 (6.7)	17 (2.9)
Other/undetermined	10	140	93	41	20	304

a. Total includes 38 cases in males and one in a female for which the year of HIV diagnosis was not reported.

Note: Figures in parentheses represent the proportion of reported cases within each year for which the exposure category was determined.

Source: NCHECR (1995).

The geographical impact of HIV infection in Australia has largely been a reflection of the predominant mode of transmission—sexual contact between men. Per capita rates of HIV and AIDS diagnoses have been substantially higher in New South Wales (see Table 2.2), and particularly in those parts of Sydney that are recognised as focal points of the gay community. In general, the capital cities have experienced higher per capita rates of HIV and AIDS diagnoses than has regional Australia.

Median ages at HIV and AIDS diagnosis have been in the low and high 30s respectively. By 1992 AIDS had become the third-greatest cause of death among people aged 25–44 years; among New South Wales men in this age group it had become the second-greatest cause.

**Table 2.2 Number of reported cases of newly diagnosed HIV infection, by sex, State and Territory, and year of diagnosis, cumulative to 31 December 1994**

State/Territory	To 1984		1985 to 1987		1988 to 1990		1991 to 1992		1993 to 1994		Cumulative total <sup>a</sup>			Rate <sup>b</sup>
	M	F	M	F	M	F	M	F	M	F	M	F	Total	
NSW	281	10	4527	200	2578	164	1300	80	900	65	9590	520	12161	201.0
Vic	212	2	1158	28	865	50	527	35	407	39	3171	154	3375	75.4
Qld	23	0	424	17	413	20	290	28	305	20	1458	85	1547	48.4
WA	24	0	287	13	186	14	108	12	88	19	696	58	755	44.1
SA	1	0	192	19	176	11	73	6	85	7	527	43	570	38.8
Tas	1	0	8	2	23	1	15	0	5	1	69	4	73	15.4
NT	0	0	24	2	18	1	11	1	16	0	78	4	82	47.9
ACT	0	0	81	3	35	2	18	5	18	3	152	13	165	54.8
Total	542	12	6701	284	4294	263	2342	167	1824	154	15741	881	18728	104.9

a. Includes people whose sex was not reported, people whose sex was reported as transsexual, and people for whom the date of HIV diagnosis was not reported.

b. Rate per 100 000 population.

Sources: NCHECR (1995).

In comparison with other developed countries, Australia ranks somewhere in the middle in terms of the per capita rate of HIV infection. Table 2.3 shows the estimated cumulative number of HIV infections per capita for selected developed countries. Spain has recently matched the United States as the developed country with the highest cumulative rate of HIV infection; these two are followed by France, Italy, Canada and Switzerland. Australia leads the next group of countries and has a higher cumulative rate per capita than the Netherlands, the United Kingdom and the Scandinavian countries.

In terms of per capita AIDS incidence, Australia's position has improved somewhat: Table 2.4 shows annual AIDS incidence per capita in selected countries. Whereas Australia ranked fifth among the selected countries in 1985, it had fallen to seventh by 1993. The annual incidence of AIDS increased more than 20-fold in Italy and Spain during this period, while incidence in Australia increased around five-fold, which is similar to the increase in Germany, the Netherlands, Sweden, the United Kingdom and the United States. In Canada and New Zealand AIDS incidence barely doubled over this period.

Australia's position also emerges favourably when countries are ranked according to the extent to which a peak in AIDS incidence has been attained. By this measure France, Italy, Spain, the United Kingdom and the United States appear to be experiencing continuing increases in AIDS incidence, while in Australia and the other countries in the Table 2.4 AIDS incidence appears to be at, or close to, a plateau.

**Table 2.3 International comparison of estimated HIV and AIDS cumulative incidence, to 31 December 1993**

Country	Cumulative HIV incidence	Rate of HIV <sup>a</sup>	Cumulative AIDS incidence	Rate of AIDS <sup>a</sup>
Australia	15 200 <sup>b</sup>	850	5 550 <sup>b</sup>	300
Canada	42 500	1 570	14 000	520
France	126 700	2 200	30 100	520
Germany, FR	32 000	390	11 250	140
Italy	112 200	1 940	21 450	370
Netherlands	8 900	580	3 025	200
Spain	168 900	4 320	24 200	620
Sweden	3 250	370	975	110
Switzerland	9 100	1 290	3 850	550
United Kingdom	40 300	690	9 000	160
United States	1 050 000	4 070	400 400	1 550

a. Per 1 million population.

b. Adjusted for under-reporting.

Note: No estimates available for New Zealand.

Source: NCHECR (1995).

**Table 2.4 AIDS incidence rates: selected OECD countries, by year of diagnosis, to 1993**

Country	To 1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993
Australia	0.1	0.3	2.6	7.1	14.5	23.7	31.9	36.0	38.6	45.8	43.9	44.1
Canada				22.2 <sup>a</sup>	21.9	31.9	38.6	45.0	46.2	48.1	52.4	47.9
France	0.5	1.7	4.2	10.4	22.3	39.4	53.5	65.8	73.8	78.4	85.2	82.3
Germany	0.1	0.6	1.6	3.8	7.1	13.2	16.6	20.5	18.7	20.6	20.3	18.8
Italy	0.0	0.1	0.6	3.4	7.9	17.8	30.7	42.6	53.8	64.5	71.3	79.1
Netherlands	0.3	1.3	2.1	4.6	9.4	16.6	22.2	26.3	27.8	29.7	33.2	28.7
New Zealand				6.1 <sup>a</sup>	4.1	8.8	12.9	20.9	20.3	20	17.4	15.0
Spain	0.1	0.4	1.3	4.4	12.3	26.8	55.8	77.5	94.6	109.2	119.5	120.2
Sweden	0.1	0.7	1.3	4.1	6.9	9.4	10.7	15.4	15.0	16.2	14.7	19.8
Switzerland	0.8	2.0	5.4	15.1	28.5	42.6	67.6	86.2	85.1	80.0	92.6	71.3
United Kingdom	0.1	0.6	1.9	4.3	8.3	11.9	15.6	18.4	21.0	23.2	25.3	26.1
United States <sup>b</sup>	6	12	24	49	74	111	138	165	185	224	289	276

a. Includes AIDS cases diagnosed up to and including 1985.

b. People who meet the 1993 AIDS case definition and whose date of diagnosis was before January 1993 were diagnosed retrospectively.

Note: Rates are per million population.

Source: NCHECR (1995).

## 2.3 PEOPLE LIVING WITH HIV/AIDS

An estimated 16 000 people have been infected with HIV in Australia, cumulative to 31 December 1994. Men who acquired HIV through homosexual contact constituted close to 85 per cent of the total number of people estimated to be living with HIV, and there were an estimated 600–700 women and 80 children living with HIV at 31 December 1994.

Among the small proportion of people who acquired HIV heterosexually, late diagnosis appears to occur more frequently than among other people with HIV. Over half of those who developed AIDS between 1991 and 1994 following heterosexual acquisition of HIV were diagnosed with HIV infection less than three months before their AIDS diagnosis; this compares with approximately one-quarter of men developing AIDS following homosexually acquired HIV (see Table 2.5). HIV diagnosis was also later among people developing AIDS in younger (less than 25) and older (45 and over ) age groups compared with people aged 25–44 developing AIDS (see Table 2.6). There was no significant difference in late diagnosis rates between metropolitan and non-metropolitan areas of residence.

**Table 2.5 Percentage of AIDS cases diagnosed: Australia, by exposure category and time since first diagnosis of HIV infection, 1991 to 1994**

Exposure category	Time from HIV diagnosis to AIDS diagnosis		
	< 3 months	3–12 months	> 12 months
Homosexual/bisexual contact	26	6	68
Homosexual/bisexual contact and IDU	12	11	77
Heterosexual contact	55	8	37
Heterosexual contact and IDU	20	8	72
Receipt of blood/blood products/tissue	37	6	57
Haemophilia/coagulation disorder	6	0	94
Mother with/or at risk of HIV infection	63	25	13
Other/undetermined	46	9	45
Proportion	28	6	66

Note: Table includes only those with known date of HIV diagnosis (66 per cent of total AIDS cases (1991 to 1994).

Source: NCHECR (1995).

Although the period of the epidemic in Australia has seen an impressive accumulation of knowledge, HIV remains an incurable infection and the inexorable progression to AIDS continues among the great majority of people who are infected.

The early hope that single antiretroviral agents would greatly retard the progressive immune destruction caused by HIV appears to have dissipated, to leave the more realistic but lesser gains of delayed progression to AIDS and a modest survival benefit. And even these gains are partly offset by the side

**Table 2.6 Percentage of AIDS cases diagnosed: Australia, by age group and time since first diagnosis of HIV infection, 1991 to 1994**

Age at AIDS diagnosis	Time from HIV diagnosis to AIDS diagnosis		
	< 3 months	3–12 months	> 12 months
< 25	35	13	52
25–44	25	8	67
45 +	33	6	61

Note: Table includes only those with known date of HIV diagnosis (66 per cent of total AIDS cases, 1991 to 1994).

Source: NCHECR (1995).

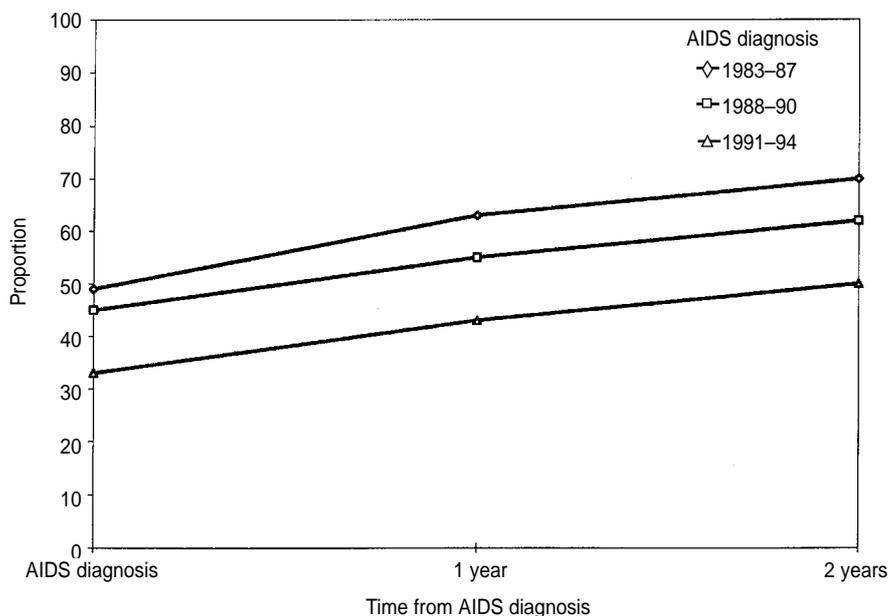
effects of antiretroviral therapy. In Australia as well as several other countries a large reduction in prescribing of zidovudine (AZT) early in the course of HIV infection has been documented and the focus of research has turned to combination antiretroviral therapy.

Despite the lack of any clear breakthrough in the treatment of HIV itself, there have been important advances in the management of the infection. Median survival following AIDS diagnosis in Australia increased from 7.7 months to 15.3 months between 1986 and 1987, the year that AZT was introduced, and has remained at approximately the latter level since. This improved survival following AIDS diagnosis is probably the result of a combination of factors. First, there is a greater awareness of the clinical manifestations of HIV/AIDS, which, coupled with earlier diagnosis, may have reduced morbidity and mortality from these manifestations. Second, management of the manifestations has improved, including prophylaxis against some of the common opportunistic infections. Finally, although antiretroviral agents such as AZT have not greatly retarded the immune destruction caused by HIV infection, they have probably contributed to delayed progression to AIDS and overall survival, as has been demonstrated in randomised clinical trials.

Increased survival following AIDS has been accompanied by a change in the spectrum of HIV clinical manifestations. Widespread use of prophylaxis for PCP (*Pneumocystis carinii* pneumonia) has produced a significant reduction in the presentation of PCP, as an AIDS-defining illness and subsequently (see Figure 2.3), while those diseases (such as cytomegalovirus) that affect the severely immunocompromised now occur more frequently (see Figure 2.4). The management focus of AIDS has partly moved, therefore, to the prevention and management of these late complications.

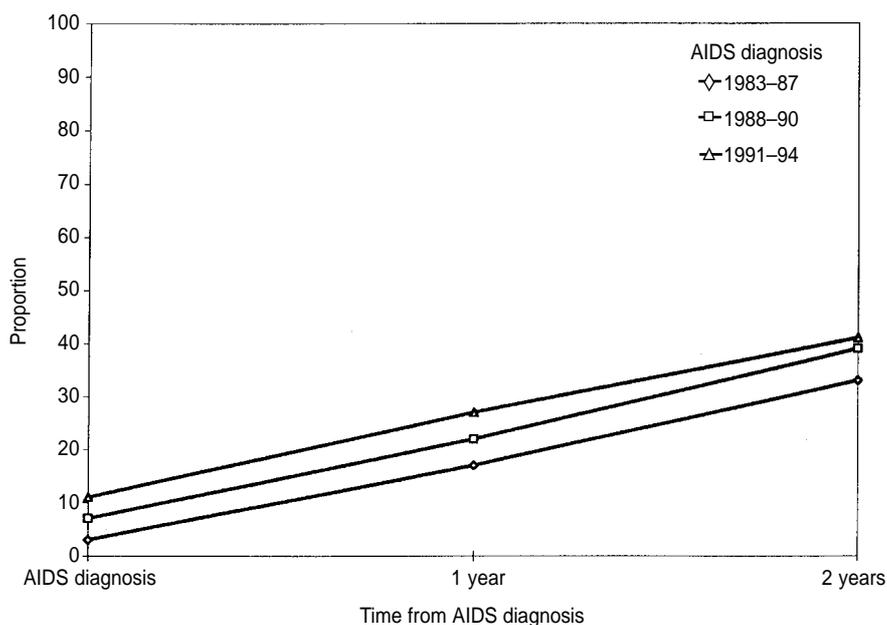
For people living with HIV/AIDS whose level of immunodeficiency places them at risk of infection, Rifabutin is now available for prophylaxis against *Mycobacterium avium* complex (MAC). It is anticipated that oral ganciclovir, which has proven benefit as primary prophylaxis against cytomegalovirus (CMV) infection, will become available in Australia in 1995. Its introduction would greatly improve the quality of life for people with CMV retinitis, who currently are required to have intravenous therapy five to seven days a week, usually in hospital, to prevent further deterioration in their vision.

**Figure 2.3** Proportion of people with AIDS who developed PCP as initial or subsequent AIDS diagnosis, by time from AIDS diagnosis and year of AIDS diagnosis, Australia, 1983 to 1994



Note: Based on a sample of 2434 AIDS cases from three HIV/AIDS units.  
Source: NCHECR (1995).

**Figure 2.4** Proportion of people with AIDS who developed CMV as initial or subsequent diagnosis, by time from AIDS diagnosis, and year of AIDS diagnosis, Australia, 1983 to 1994



Note: Based on a sample of 2434 AIDS cases from three HIV/AIDS units.  
Source: NCHECR (1995).

## VULI'S LOVE OF LIFE

Vuli is a happy, bright-eyed 8-year-old boy whose love for life is evident as he dives around the comfortable Glebe apartment he shares with his twin brother Bheki and foster mother Suzi, embarking on a ball game here, an intensive conversation there.

On a cold winter's night in inner Sydney, the brothers have just watched one of their favourite soap operas and Vuli is in the kitchen recounting to Suzi how tonight's episode had an unexpected and sad ending. Vuli admits that sometimes he is a bit sad because he believes he will probably die when he's about 37 years old, about the age his mother and father were when they died.

Vuli's mother, Megan Schlunke, was an adventurous young Australian woman who, on a visit to Zimbabwe met and married a handsome Zimbabwean man, Richard Mkwana. The couple moved back to Australia to live and Megan gave birth to twins—Bheki and Vuli. Not long after, Richard became very sick and eventually he was diagnosed as having AIDS. Megan was also tested and her results were HIV positive.

'They could not bring themselves to have the boys tested until they were 3 years old,' Suzi—Megan's best friend and now foster mother to the children—said. 'The results showed that Bheki was anti body negative, Vuli was positive.'

'The next few years were pretty chaotic,' according to Suzi. 'Megan threw herself into HIV/AIDS work and produced the first Needs Assessment Report for HIV Women, which literally nearly killed her. Both Richard and Megan became very ill and both were in and out of hospital. They wanted to die at home and, although I was a trained nurse the hospital in Sydney was very much against letting them go home. Eventually I picked them up from the hospital in my small car—they were only semi-conscious. Richard died in July 1991 on the night he came home. Megan died six weeks later. She was home for just three days.'

Megan and Richard had 'willed' the boys to Suzi, who had recently been married. 'It certainly took a toll on my marriage and then later when my own baby was still-born, that was the end for us,' Suzi said. 'Our divorce comes through next month.'

But Suzi said she enjoys every minute of bringing up the boys. 'I treat them both the same. Vuli has no symptoms of AIDS as yet and is not on any medication, so I don't see the point in pampering him more than Bheki,' she added.

'Vuli has blood tests every six months to monitor his T-cell levels. He was upset that he could not explain why he had the tests to his mates at school. So I approached the school principal with the support of the Paediatric AIDS Unit at Prince of Wales Hospital. We set in train a planned disclosure in which Vuli played a pivotal role.

'Firstly the principal spoke to a meeting of the teachers. The teachers produced a comprehensive HIV/AIDS education program. There was a public meeting of the parents and then Vuli and Bheki in the 'news' session in the class got up in front of everyone and told them he had HIV.'

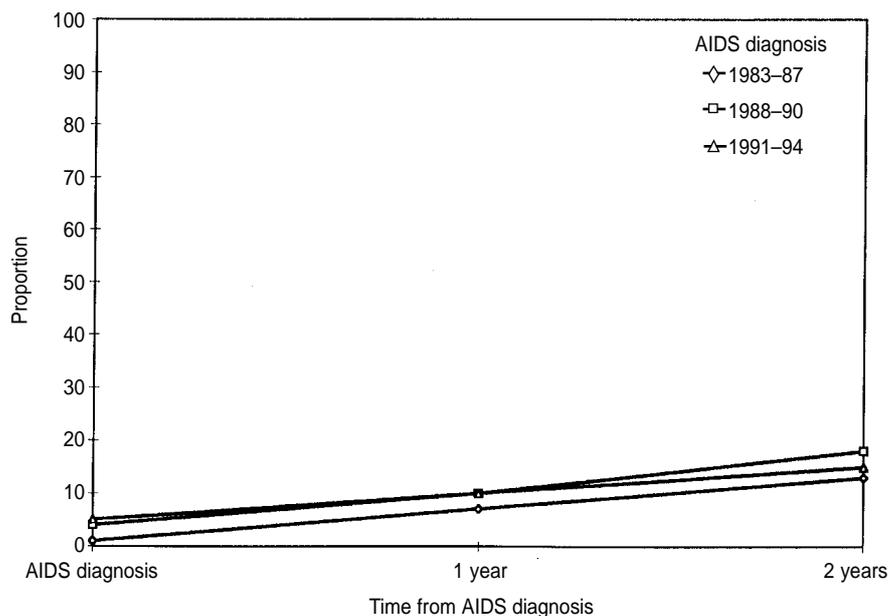
'The kids wanted to know things like how did he get it, how does it feel, but most were not that interested,' Vuli explained. 'It didn't change anything between my friends and me, except some of the kids sing a silly song about it's 'gay school', he said with a frown.

Sitting in the family kitchen that cold night chatting about AIDS, Bheki points out that whatever happens you always die if you have AIDS. 'Yes, but whatever happens, eventually everybody dies,' Vuli chipped in with a knowing grin.

AIDS dementia complex is another condition that occurs predominantly at advanced stages of immunodeficiency; it is associated with considerable morbidity for people living with HIV. Its incidence has changed little in the past decade (see Figure 2.5). Therapy with AZT appears to reverse or stabilise AIDS dementia complex in approximately half of cases.

The recent finding that AZT given in pregnancy markedly reduces the perinatal transmission of HIV has limited application in Australia because of the low rate of HIV in women, but it should have an impact on rates of infant infection in many other countries. This finding will also stimulate development of strategies appropriate to the developing world, where the vast majority of women with HIV live.

**Figure 2.5 Proportion of people with AIDS who developed AIDS dementia complex as initial or subsequent AIDS diagnosis, by time from AIDS diagnosis, and year of AIDS diagnosis, Australia, 1983 to 1994**



Note: Based on a sample of 2434 AIDS cases from three HIV/AIDS units.  
Source: NCHECR (1995).

## 2.4 HOMOSEXUALLY ACTIVE MEN

Sex between men has been the major mode of transmission of HIV in Australia since the beginning of the AIDS epidemic. The proportion of cases of HIV and AIDS attributed to homosexual contact has been very high and relatively constant over time. By the end of 1994, 90 per cent of cumulative AIDS cases in adults among persons whose exposure category was reported had occurred in men with a history of homosexual contact. During 1994,

85 per cent of reported cases of newly diagnosed HIV infections, and 88 per cent of newly acquired HIV infections among people whose exposure category could be determined were in men with a history of homosexual contact.

Although the proportion of new diagnoses of AIDS and HIV occurring in homosexually active men has remained high, there has been a considerable fall in the absolute number of new diagnoses of HIV in this group, decreased from a peak of 2284 in 1987 to 772 in 1994. In cohort studies, the rate of new HIV infections among homosexually active men was first high and then declined through the late 1980s. In the Sydney AIDS Prospective Study, the rate of seroconversion was 10 per cent a year in 1984 but had decreased to about 1 per cent a year by 1990 (NCHECR, 1995). Follow-up of this cohort suggests that the rate has remained low (see Table 2.7).

**Table 2.7 Estimated incidence of HIV infection: the Sydney AIDS Prospective Study**

Year	N <sup>a</sup>	Person-years follow-up	Estimated number of new HIV seroconversions	Incidence <sup>b</sup>
1984	493	196.5	20	10.2 (6.2, 15.7)
1985	499	432.0	24	5.6 (3.6, 8.3)
1986	392	356.4	18	5.1 (3.0, 8.0)
1987	327	306.9	6	2.0 (0.7, 4.3)
1988	290	268.3	7	2.6 (1.0, 5.4)
1989	243	225.6	5	2.2 (0.7, 5.2)
1990	209	189.6	2	1.1 (0.1, 3.8)
1991 to 1994	169	388.6	1	0.3 (0.0, 1.4)

a. Number of study participants with last recorded HIV test in this year. Total number of study participants initially negative for HIV = 531.

b. Incidence per 100 person-years; 95 per cent confidence interval.

Source: NCHECR (1995).

Calculation of HIV incidence rates based on people attending Albion Street Centre in Sydney also showed a fall in the incidence of HIV among men reporting homosexual contact, from 5.7 per cent in 1985 to 1.9 per cent in 1990. In sentinel surveillance at STD clinics, the prevalence of diagnosed HIV infection among those tested for HIV antibodies for the first time between 1992 and 1994 was 0.5 per cent in men and 2.8 per cent among those men reporting a history of homosexual contact.

Of some concern are preliminary data from a current cohort investigation, the Sydney Men and Sexual Health study, suggesting that the rate of new infections in men in this study may be about 3 per cent a year. But only 18 per cent of men in this study have had a documented second HIV test result after their first negative result, and it is possible that men who were at high risk

were more likely to have been tested. This would result in overestimation of the true rate of new HIV infection in this cohort (Prestage et al. 1995b).

The general decline in HIV incidence among homosexually active men is confirmed by the results of mathematical back projection from reported AIDS cases. Estimated annual incidence of HIV infection among homosexually active men decreased from a peak of 2840 in 1984 to around 400 in 1990.

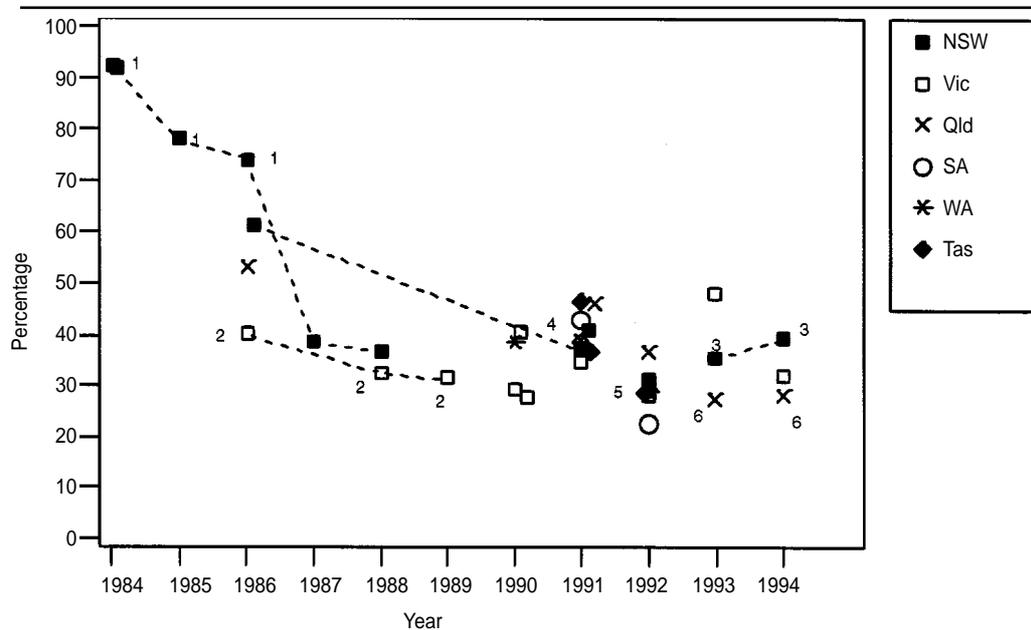
Internationally, similar patterns of HIV infection in homosexually active men, with a peak of new infection in the mid-1980s followed by a rapid fall, have been reported. Cohort studies in the United States showed peak annual rates of infection in the early to mid-1980s that were as high as 20 per cent in 1982 in San Francisco and 8 per cent in the four cities of the Multicentre AIDS Cohort Study (MACS) (Kingsley et al., 1991). Rates in these cohorts then rapidly dropped to about 1 per cent by 1985 (San Francisco) and 1987 (MACS). Although some of this drop may have been the result of men at higher risk becoming infected first, leaving a lower risk in those remaining uninfected in the cohort, more recent United States cohort studies have confirmed continuing low rates of HIV seroconversion. The San Francisco Young Men's Health Study found a rate of new infection of 2.6 per cent per year in homosexually active men aged 18–29 during 1992–93 (Osmond et al. 1994). Back projection has also shown that the rate of infection in homosexually active men peaked in the United States and European countries in the mid-1980s and then fell substantially.

Although there is no disputing the rapid decrease in new infections transmitted through sex between men in the second half of the 1980s, the possibility of a second wave of new HIV infection among homosexually active men remains a cause for concern. National reporting of newly acquired HIV infection suggests an increase in the number of reports of newly acquired HIV infection among homosexually active men—from 69 in 1991 to 174 in 1993—probably largely attributable to improvements in surveillance. The number of new infections reported in 1994 (159) was less than that in 1993.

Also of concern has been an increase in the proportion of men with gonorrhoea who have anorectal infection and in the number of men with anorectal gonorrhoea, which may indicate an increase in unsafe sexual practices. In Victoria the number of cases of anorectal gonorrhoea among men increased from 20 in 1990 to 51 in 1993, while overall counts of gonorrhoea in men remained roughly constant.

Surveys of sexual behaviour in homosexually active men suggest that there was a decrease in the practice of anal intercourse before the widespread recommendations on condom use (see Figure 2.6). From about 1986 there is evidence for increased use of condoms for anal intercourse. There has been a further decline in the percentage of men engaging in unprotected anal intercourse between 1986 and around 1990 (see Figures 2.6 and 2.7), although

**Figure 2.6 Percentage of men engaging in unprotected anal intercourse with regular or casual partners: Australia, 1984 to 1994**



Notes:

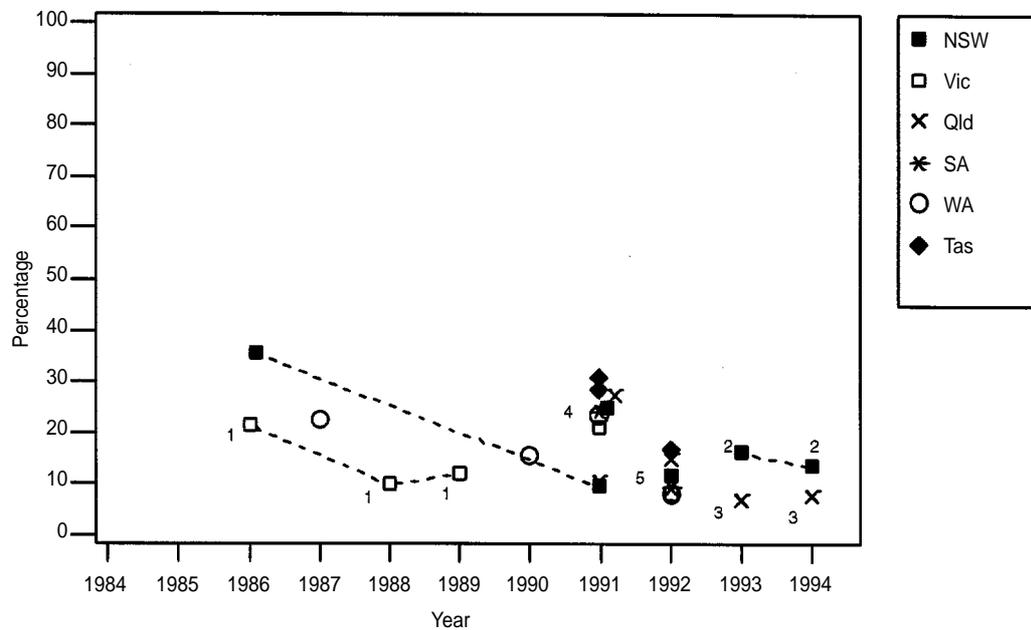
1. Sydney AIDS Prospective Study. 1984 within a three-month period, otherwise six months. Prior to 1987 any anal intercourse. 1987 and 1988 any unprotected anal intercourse within six months prior to interview.
2. Melbourne University Prospective Study—unprotected anal intercourse within one month prior to interview.
3. Sydney Men and Sexual Health—unprotected anal intercourse within six months prior to interview.
4. Most points for 1991 are from the national evaluation of gay/bisexual campaigns.
5. Most points for 1992 are from the gay community – attached sample of Project Male Call.
6. Popular People Project—unprotected anal intercourse within two months prior to interview.

Source: Crawford et al. (1995).

only limited data are available for this period. Since 1990 levels of unprotected anal intercourse appear to have remained fairly stable. Recent data show that around one-third of homosexually active men in gay communities report having engaged in unprotected anal intercourse with either a regular or a casual partner at least once in the six months prior to interview. This proportion has decreased from around 50 to 60 per cent in 1986 and around 90 per cent in 1984. As Figure 2.7 shows, there has also been a decline in the proportion of homosexually active men having unprotected anal intercourse with casual partners, to a current level of around 10 per cent.

Time trends for unprotected anal intercourse are consistent from study to study and across different study samples, age groups, self-attributed sexual identity, and HIV antibody status. The observed decrease in unprotected anal intercourse among homosexually active men parallels the decline in incidence of HIV in this population and is a plausible explanation for part of the decline. The decrease has been sustained since around 1989, although there is a suggestion from the data that unprotected anal intercourse with regular partners may be increasing slightly (see Figure 2.6).

**Figure 2.7 Percentage of men engaging in unprotected anal intercourse with casual partners: Australia, 1984 to 1994**



1. Melbourne University Prospective Study (A2)—within one month prior to interview.
  2. Sydney Men and Sexual Health (A7)—within six months prior to interview.
  3. Popular People Project—within two months prior to the study.
  4. Most points for 1991 are from the national evaluation (A3) and refer to six months prior to the survey.
  5. Most points for 1992 are from Project Male Call (A5) and refer to six months prior to interview.
- Source: Crawford et al. (1995).

A steady reduction in the incidence of HIV infection among homosexually active men occurred from the mid-1980s, but this group continues to be the most severely affected by the HIV epidemic, in terms of both new infection and the burden of illness. Although there is no indication of a recent upward trend in transmission rates, continuing surveillance of the incidence of HIV and other STDs in homosexually active men is essential. Another priority is research to identify the risk associated with sexual practices other than unprotected anal intercourse and to define correlates and predictors of sexual behaviour that may provide a basis for improving prevention activities.

### 2.4.1 1995 update

In the first half of 1995, 83 newly acquired HIV infections and 272 new diagnoses of HIV infection in homosexually active men were reported to the National Centre in HIV Epidemiology and Clinical Research; this compares with 84 newly acquired infections and 353 newly diagnosed infections reported in the first half of 1994. It is probable that some duplicate registrations have not yet been detected and corrected and that some diagnoses remain to be reported

nationally. The available 1995 data thus show no clear increase in levels of new HIV infection and diagnosis among homosexually active men.

## 2.5 PEOPLE WHO INJECT DRUGS

The earliest evidence of HIV infection among injecting drug users (IDUs) in Australia was the 1983 diagnosis of AIDS in a man with a history of both injecting drug use and homosexual contact. Of the 11 950 new diagnoses of HIV infection reported in Australia to December 1994 in people aged 13 years or over for whom exposure category was available, 8.1 per cent were in people with a history of injecting drug use. Of these, 38 per cent were men who also had a history of homosexual contact. Since the value of routine surveillance reports is limited by their dependence on patterns of voluntary, named testing and self-reported exposure history, a number of approaches have been used to estimate HIV prevalence among IDUs.

Early studies were predominantly carried out among IDUs in contact with health services such as STD clinics, methadone treatment centres or health centres specifically targeting IDUs. More recent studies have recruited IDUs through social networks and needle and syringe exchange programs and have collected detailed information on demographic and behavioural factors.

In early studies of IDUs estimates of HIV prevalence ranged from 0.5 per cent to 14 per cent. Prevalence was higher in men (1 per cent to 18 per cent) than in women (0 per cent to 6.7 per cent) and was highest in men with a history of homosexual contact, for whom prevalence estimates were from 13 per cent to 32 per cent compared with 1.6 per cent to 5 per cent in men reporting heterosexual contact only. Reported HIV seroprevalence tended to be higher in Sydney than in Melbourne, Adelaide and Perth.

The first national study of HIV prevalence in IDUs, carried out in two rounds during 1989–90 in Perth, Brisbane, Melbourne and Sydney, reported prevalence close to 7 per cent in Sydney and around 2 per cent in the other cities. Similar results were obtained when the survey was repeated in 1994. HIV prevalence was generally higher in men than in women, with the highest prevalence again being in men who reported homosexual contact (20.6 per cent compared with 1.6 per cent in heterosexual men). These two studies showed that between 1989 and 1990 self-reported unsafe injecting behaviour in the preceding month declined from 20–40 per cent to 10 per cent.

Similar results were obtained in a national survey of HIV prevalence among people attending needle and syringe exchanges in 1995 (see Table 2.8). Specimens adequate for testing were provided by 1005 clients (42 per cent). The HIV prevalence overall was 2 per cent and was again significantly higher in males who described themselves as homosexual or bisexual compared with survey participants who described themselves as heterosexual (see Table 2.9).

## WHO WILL SPEAK FOR INJECTING DRUG USERS?

A chance meeting in a Sydney street in the early 1980s between Dr Alex Wodak and Professor David Cooper (now head of the National Centre in HIV Epidemiology and Clinical Research in New South Wales) led Alex into a commitment to working with others to stop the spread of HIV/AIDS and other blood-borne diseases through injecting drug use.

'David was off to a session at the Immunology B Clinic, which was frequented mainly by gay men,' Alex said. 'The A Clinic was for patients with "respectable" immunological diseases; the B Clinic was mainly for people with HIV. He was looking particularly depressed and he said he had just seen an eminent doctor's son who was HIV positive, gay and also injected drugs.'

'I thought—here we go! We already knew that HIV had got out of control among IDUs in New York and other cities and I was very concerned. I knew then what would happen in places like Taylor Square (a Sydney drug users' haunt) if I and others just looked the other way.'

In the early days of the AIDS epidemic the gay community was smart, educated, articulate and they were going to change the course of the epidemic for themselves. But who was going to speak for the drug users? They didn't seem organised enough then to fight the battles.' Alex got together a few other people, including a gay AIDS educator and other health workers, and they held a public meeting. 'From this meeting we formed an organisation called ADIC—the AIDS Drug Information Collective. The aim was to get user groups established and supported by clinicians, researchers, the drug squad—people working together to stop the spread of HIV through infected needles,' he said.

In the succeeding years Alex worked with a wide variety of people, including governments and community groups, to promote the introduction and implementation of needle exchange programs and to inform users of the risks associated with sharing needles. Today Australia has one of the lowest transmission rates of HIV through injecting drug use in the world. 'Most users are well aware of the risks of sharing and usually do so only in the confines of their own family and friends,' Alex said. 'But there are still many challenges ahead to curb the spread of other, more virulent diseases such as hepatitis C,' he added.

Alex is director of the Alcohol and Drug Service at Sydney's St Vincent's Hospital. He has a particular interest in drug use in prisons and the threat it poses in the transmission of HIV/AIDS.

'While HIV in Australian prisons is not widespread at present, the potential is there, with about 60 per cent of inmates incarcerated for drug-related crimes,' he warned. 'HIV and other viruses are spreading more than we generally acknowledge. We need to use prisons only as a last resort and cut the prison population. This means more non-custodial sentencing options and making methadone programs more freely available.'

Alex finds that prisoners are at a very difficult time of their lives and have few opportunities to avoid the infections (unlike the community). 'Prison authorities are fearful of any measures that may compromise the safety of prison officers, like supplying clean needles to inmates. This is understandable but we still need to come up with effective and acceptable responses.'

'It's a very serious situation which must be faced by governments, no matter how difficult,' he said.

**Table 2.8 HIV prevalence in injecting drug users, by sex and sexual preference**

Study sub-group	Males		Females	
	Number tested	Per cent with HIV antibodies	Number tested	Per cent with HIV antibodies
ASHIDU (1994)	516	3.9	276	1.1
Heterosexual	453	1.5	214	0.9
Homosexual/bisexual	63	20.6	63	1.6
National needle and syringe exchange program survey (1995)	637	2.4	332	1.5
Heterosexual	552	0.7	237	1.3
Homosexual/bisexual	77	13.0	87	2.2

Source: NCHECR (1995).

**Table 2.9 HIV prevalence in injecting drug users, years of drug use, last drug used, and sexual preference**

	Homosexual/bisexual		Heterosexual	
	Number of respondents	Number (%) with HIV antibodies	Number of respondents	Number (%) with HIV antibodies
Years of drug use				
Less than 3 years	30	1 (3.3)	117	0
3 to 6 years	37	2 (5.4)	126	0
Over 6 years	102	9 (8.8)	550	8 (1.4)
Total	169	12 (7.1)	793	8 (1.0)
Last drug used				
Heroin	77	7 (9.1)	335	3 (0.9)
Methadone	15	0	158	1 (0.6)
Amphetamines (speed)	51	3 (5.9)	149	0
Cocaine	4	1 (2.0)	14	1 (7.1)
Other	22	1 (4.5)	101	3 (3.0)
Total	169	12 (7.1)	793	8 (1.0)

Source: National needle and syringe exchange program survey (see NCHECR 1995).

Surveys of prison entrants have shown that nearly half of them have a history of injecting drug use. HIV prevalence among prison entrants has remained under 0.5 per cent between 1990 and 1994. Surveys of prisoners and people with a history of imprisonment show that about half of them continue to inject, albeit less frequently, while they are imprisoned and that the great majority use unsterilised equipment.

Apart from homosexual contact in men, few behavioural factors have emerged as significantly associated with HIV infection among IDUs. A review of behavioural studies suggests that in the early and mid-1980s the sharing of

injecting equipment was common but had declined in frequency by 1987–88; there was a further decline in 1993–94. Throughout this period there has been very little change in rates of condom use with casual sexual partners, suggesting that IDUs have come to perceive themselves as being at risk of viral transmission from injecting rather than from sex. Two studies found that among heroin users HIV antibodies were detected only in users who began injecting more than six years ago, whereas they were detected in amphetamine injectors who started injecting more recently.

HIV incidence estimates for IDUs have been obtained from back projection based on a limited number of AIDS cases. Estimated HIV incidence in heterosexual IDUs rose from 20 cases in 1984 to 80 cases in 1987; this was followed by a decline to 20 cases per year for 1993. The number of cases was too small to make similar estimates for male homosexual IDUs. The only direct measure of incidence in IDUs comes from a cohort study in which one seroconversion has been observed in 470 person-years of follow-up, giving a rate of 0.2 per 100 person-years (95 per cent CI 0.03–1.4 per 100 person-years).

In contrast with HIV, both the prevalence and incidence of hepatitis C infection among IDUs in Australia have been high, and the patterns of infection have differed from HIV infection patterns. Hepatitis C prevalence is significantly higher in heterosexual IDUs compared with homosexual male IDUs and in heroin users compared with amphetamine users, even after taking account of the duration and frequency of injecting. Prevalence also varies between cities, being higher in Melbourne and Sydney than in Perth and Adelaide. The first incidence studies showed rates of new infection of around 15 cases per 100 person-years, but there is some indication from a cohort study that incidence has fallen recently (see Table 2.10).

**Table 2.10 Hepatitis C virus incidence**

Study group	Seroconversions	Incidence <sup>a</sup>
Prison entrants (drug users) 1991 to 1992	10	38 (19.1–76.4)
Primary health care 1993 to 1994	9	15 (7.3–30.4)
Cohort study (preliminary data) 1990 to 1992	4	11 (4.3–30)
Cohort study (preliminary data) 1993 to 1995	15	4 (2.2–5.9)

a. Incidence per 100 person-years; 95 per cent confidence interval.  
Source: NCHECR (1995).

In summary, with the exception of male IDUs who also have a history of homosexual contact, the prevalence of HIV infection among IDUs in Australia is low (less than 5 per cent) in comparison with a number of other developed countries (see Table 2.11). This pattern has been consistently reported in different populations of IDUs recruited using different strategies and it suggests that male IDUs in Australia mainly became infected through homosexual sex.

**Table 2.11 HIV prevalence among injecting drug users: selected cities, 1990 to 1992**

HIV prevalence < 5 per cent	HIV prevalence 5–10 per cent	HIV prevalence 10–40 per cent	HIV prevalence ≥ 40 per cent
Athens, Greece	Cleveland, US	Berlin, Germany	Amsterdam, Holland
Denver, US	Detroit, US	Central Thailand	Chiang Mai, Thailand
Glasgow, Scotland	New Haven, US	Edinburgh, Scotland	Bangkok, Thailand
Houston, US	New Orleans, US	Florence, Italy	Manipur, India
Lisbon, Portugal	Poland (no city specified)	Miami, US	Madrid, Spain
London, England	Salt Lake City, US	Montreal, Canada	New York City, US
Los Angeles, US	San Francisco, US	Paris, France	Newark, US
Naples, Italy		Rome, Italy	Rangoon, Myanmar
Tacoma, US		Rio de Janeiro, Brazil	San Juan, US
Toronto, Canada		Stockholm, Sweden	
		Vienna, Austria	
		Washington, US	

Source: NCHECR (1995).

## 2.6 ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

The possibility of a major outbreak of HIV infection among Aboriginal and Torres Strait Islander people has been cause for concern almost since the AIDS epidemic began in Australia.

So far, the information available from routine surveillance indicates that the rates of HIV infection among Aboriginal and Torres Strait Islander people are similar to those in the non-indigenous population (see Table 2.12). But it appears that the rate of HIV diagnosis in Aboriginal and Torres Strait Islander people is increasing, in contrast with rates in the overall Australian HIV epidemic, which reached a peak in the early to mid-1980s. New HIV diagnoses in Australia between 1992 and 1994 constituted only 17 per cent of cumulative HIV notifications, whereas among Aboriginal and Torres Strait Islander people during the same period new HIV diagnoses constituted 50 per cent of cumulative diagnoses (see Table 2.13).

Possible biases in these data include misclassification or non-reporting of Aboriginality and the non-uniform surveillance mechanisms for HIV infection that are used by the States and Territories—some do not include data on Aboriginality; others have included such data only in recent years. The possibility of relative underdetection of early HIV infection among Aboriginal and Torres Strait Islander people also exists.

Indirect sources of data support routine surveillance in indicating a currently low prevalence of HIV among Aboriginal and Torres Strait Islander people. First, HIV prevalence among antenatal women, measured through voluntary

antenatal screening and anonymous delinked surveys, has remained extremely low. Although the proportion of Aboriginal and Torres Strait Islander women included in these prevalence surveys is unknown, it is probable that a substantially increased prevalence among such women would have been detected. Second, all States and Territories perform HIV testing on a proportion of prison entrants to the end of 1994—virtually all entrants are tested in New South Wales,

**Table 2.12 Rates of HIV infection per 100 000 population, cumulative to 31 December 1994, by State and Territory**

State/ Territory	Aboriginal and Torres Strait Islander	Non-indigenous	Total population
NSW	24 <sup>a</sup>	26 <sup>a</sup>	207
Vic	na	na	76
Qld	64	52	53
WA	34	46	46
SA	68	39	39
Tas	na	na	16
NT	15	56	46
ACT	na	na	57
Total			109

na Not available.

a. Rates based on new HIV diagnoses 1992–1994; total population rate cumulative to December 1994.

Note: Table based on population estimates from 1991 census (Australian Bureau of Statistics).

Source: NCHECR (1995).

**Table 2.13 Exposure category for HIV notifications among Aboriginal and Torres Strait Islander people, by year and sex**

Year	Exposure category cases (percentage)											Total (per cent)		
	Hom./bis.		+IDU		IDU		Hetero.		Other/ unknown		Total		A&TSI	Aust
	Hom./bis.													
M	M	M	F	M	F	M	F	M	F	M	F			
1985–88	15	2	1	0	1	1	0	0	19	1	20	11	054	
												(22)	(59)	
1989–91	12	5	2	0	3	2	1	0	23	2	25	4	428	
												(28)	(24)	
1992–94	22	3	1	0	7	8	3	1	36	9	45	3	239	
												(50)	(17)	
1985–94	49	10	4	0	11	11	4	1	78	12	90	18	721	
A&TSI	49	10	4		22		5		90					
Total	(55)	(11)	(4)		(24)		(6)		(100)					
Australian														
Total	(81)	(3)	(5)		(7)		(4)		(100)					

Note: No data available for the Australian Capital Territory, Tasmania, Victoria and New South Wales (pre-1991).

Source: NCHECR (1995).

Queensland and Victoria. In the Northern Territory, which has the highest proportion of Aboriginal and Torres Strait Islander people in both the overall and the prison population, 75 per cent of prison entrants have been tested since 1991. Of the over 5000 HIV tests performed during that time there were only two seropositive results, neither of which was in an indigenous person.

Although there is some similarity in reported modes of transmission of HIV among Aboriginal and Torres Strait Islander people and people from non-indigenous backgrounds, among whom sex between men is the predominant HIV transmission mode, there has been an increasing proportion of HIV diagnosis in Aboriginal and Torres Strait Islander people reporting heterosexual contact as the likely mode of transmission (see Table 2.13). Among Aboriginal and Torres Strait Islander people the cumulative proportion of HIV cases attributed to heterosexual contact (24 per cent) is much higher than in the non-indigenous HIV-infected population (7 per cent), and half the cases have been reported since 1992, in contrast with the non-indigenous cases, of which over 80 per cent were reported before 1992. This may suggest an increasing rate of heterosexually acquired HIV infection among Aboriginal and Torres Strait Islander people, or it could be explained by more active surveillance, including contact tracing, in recent years. As in the non-indigenous population, the possibility exists that heterosexual exposure is incorrectly attributed, but the equal number of male and female cases attributed to heterosexual contact argues against significant misclassification bias.

Predictions of a large HIV epidemic among Aboriginal and Torres Strait Islander people have been stimulated by the documentation of very high rates of other STDs in this population. As well as representing an important health problem in their own right, other STDs are believed to increase the likelihood of HIV transmission, particularly if they cause genital ulceration. Although STD rates among homosexual men and female sex workers have declined substantially since the start of the AIDS epidemic, a similar fall in STD rates has not been observed among Aboriginal and Torres Strait Islander people.

A large HIV epidemic among Aboriginal and Torres Strait Islander people would have immense social and health ramifications. The already considerable imbalance in health status between Aboriginal and Torres Strait Islander people and non-indigenous people would be amplified. Existing health problems among Aboriginal and Torres Strait Islander people—such as malnutrition, tuberculosis and other infectious diseases—would be exacerbated and the current life expectancy gap of 20 years between Aboriginal and Torres Strait Islander people and non-indigenous Australians could widen.

Although HIV prevalence among Aboriginal and Torres Strait Islander people appears to be low, the recent increase in the rate of diagnosis, including the trend to a higher proportion of heterosexually acquired cases of HIV, and continuing high rates of other STDs emphasise the urgent and continuing need for improved HIV/STD prevention and control programs.

### 2.6.1 1995 update

In the six months from 1 January to 30 June 1995 there have been six (three male, three female) newly diagnosed cases of HIV among Aboriginal and Torres Strait Islander people, from a total of 455 newly diagnosed cases of HIV in Australia. This represents a rate of notification among Aboriginal and Torres Strait Islander people comparable with that between 1992 and 1994. Five of the six cases reported heterosexual contact as their HIV exposure category, lending further support to the hypothesis of an increasing proportion of infections being transmitted through heterosexual contact.

## 2.7 MEDICALLY ACQUIRED HIV INFECTION

The number of new HIV infections that occurred as a result of blood transfusions between 1981 and May 1985, when universal antibody testing of blood donations was introduced, appears to reflect the overall increase in the prevalence of HIV infection in Australia around that time (see Table 2.14). In late 1984, before the introduction of universal screening of blood and tissue in Australia, donor deferral based on interviewing donors about sexual and drug injecting history and other factors was introduced to reduce the risk of transmission of HIV. Only four people (2 per cent of all cases) who received a blood transfusion between November 1984 and May 1985 were found to have been infected with HIV as a result of the transfusion (see Table 2.14).

**Table 2.14 Australian cases of transfusion-acquired HIV, by year of infection**

Year of infection	Number	Percentage of all cases
To 1981	12	6
1981	20	11
1982	32	17
1983	54	29
January to November 1984	51	27
November 1984 to May 1985	4	2
Not known	16	8

Note: 'Not known' includes cases of infection before May 1985 for which the date of infection could not be established.  
Source: NCHECR (1995).

Between 1979 and 1984 people with hereditary bleeding disorders were almost exclusively treated with blood products derived from Australian blood donations. With an estimated HIV prevalence that attained 30 per cent, people with haemophilia were the population group at the greatest risk of acquiring HIV in Australia around this time. The safety of blood products used in the treatment of people with haemophilia was substantially improved with the introduction of donor deferral and heat treatment of Australian lyophilised concentrates in late 1984 and the universal screening of blood donors in May 1985.

**Table 2.15 Diagnosed cases of HIV and AIDS and deaths in Australia among people with medically acquired HIV infection, by exposure category, to 31 December 1994**

	Haemophilia	Transfusion acquired	Artificial insemination	Surgical patients
HIV diagnoses	264	189	4	4
AIDS case reports	84	112	3	1
Reported deaths	92	123	3	1

Source: NCHECR (1995).

Other cases of medically acquired HIV in Australia have been through semen donation for artificial insemination (before May 1985). The only medically acquired cases known to have been transmitted since May 1985 involved four surgical patients who acquired HIV in a single episode in 1989 (see Table 2.15).

The risk of acquiring HIV infection via donated blood or tissue was essentially eliminated in May 1985. Nevertheless, the possibility remains that a unit of HIV-infected blood may have been used for transfusion in Australia since 1985, as a result of a blood donation collected from a donor recently infected with HIV who had not yet formed detectable levels of HIV antibodies. Although the cumulative likelihood of this increases with time, the chance that a unit of blood is contaminated with HIV remains extremely small and must be viewed in the broader context of the benefits provided by donated blood or tissue.

## 2.8 SEX WORKERS

Sex workers have been considered to be at increased risk of HIV infection because of their high number of sexual partners, their increased potential for infection with STDs, and other associated behaviours such as injecting drug use. In a number of countries, particularly in Africa and Asia, female sex workers have been documented as having a high prevalence of HIV infection, as have their male partners (see Table 2.16). In contrast, HIV prevalence among female sex workers in Australia has been very low. On the other hand, male sex workers whose clients are male have a substantial risk of HIV infection, reflecting the predominance of sex between men as the principal route of HIV transmission in Australia.

Information on a history of sex work is not routinely collected in national surveillance for newly diagnosed HIV infection in Australia. But information on HIV antibody testing in women who identify themselves as sex workers and who attended one of six metropolitan public STD clinics has been routinely collected since 1992. Overall, nearly 4000, or about 10 per cent, of the women seen at the clinics between 1992 and 1994 reported a history of sex work and 13 per cent of these women also reported a history of injecting drug use. More than 80 per cent were tested for HIV antibodies and only one woman, who originated from a country in South-East Asia, was newly

diagnosed with HIV infection. The prevalence of specific STDs—gonorrhoea, syphilis and chlamydia—in female sex workers also remained low (less than 3 per cent) between 1992 and 1994. There are no comparable data on the extent of HIV infection in men with a history of sex work. In one small Sydney study, the prevalence of HIV infection among men attending a needle exchange who gave a history of sex work was 23 per cent.

**Table 2.16 Prevalence of HIV infection among sex workers, by geographic region, study population and time interval**

Geographic region	Study population	Interval of time	Prevalence	
			Male	Female
Western European Region				
European Working Group on HIV infection in female prostitutes	Voluntary HIV antibody testing of female prostitutes	Sept 1990–Nov 1991	–	5.5
	Injecting drug use		–	31.8
	Non-injecting drug use		–	1.5
Sub-Saharan Africa				
Zaire	Voluntary HIV antibody testing of female prostitutes in Kinshasa	5 months over 1988–89	–	35.0
Southern Asia				
India	Voluntary testing of patients attending an STD clinic in Pune	May 1993–July 1994	–	45.3
Thailand	Voluntary testing of male commercial sex workers in Chiang Mai	December 1993	20.1	–
Thailand	Voluntary HIV antibody testing of brothel-based female prostitutes in Chiang Mai	June 1989 June 1991	– –	3.5 <sup>a</sup> 15.0 <sup>b</sup>

a. Median value. Range = 0–44.

b. Median value. Range = 2–63.

Source: NCHECR (1995).

Among patients attending a public STD clinic in Sydney between July 1988 and June 1990, almost all diagnoses of gonorrhoea in female sex workers occurred in women who originated from countries in South-East Asia. The high prevalence of hepatitis C virus infection (56 per cent) among IDUs with a history of sex work and attending a primary care facility in Sydney suggests that sex workers may also be at risk of HIV infection if they inject drugs.

Although several behavioural studies of sex workers have been done their interpretation is hindered by variations in legislation and in the social framework within which sex work takes place in Australia. It appears that

condom use with clients in some segments of the industry now approaches 100 per cent, but the heterogeneity of working conditions and circumstances included in the term 'sex work' makes broad generalisations impossible. It is, however, probable that large-scale change towards increased condom use has occurred in legal brothels in the last decade. Behavioural data pertaining to workers outside the legally operating industry are too limited to allow for any conclusions. There have also been very limited behavioural studies of sex workers originating from South-East Asia.

## 2.9 HETEROSEXUAL CONTACT

Although in Australia HIV has been transmitted heterosexually, both from men to women and from women to men, this mode of transmission remains rare. It has been monitored using a range of methods, among them national surveillance for newly diagnosed HIV infection and AIDS, voluntary HIV antibody testing of patients attending STD clinics, mandatory HIV antibody testing of blood donations and Defence Force entrants, and anonymous unlinked HIV seroprevalence studies in pregnant women and newborns. Each method has advantages and disadvantages, but all are consistent in indicating the rarity of heterosexual HIV transmission. They do, however, also suggest that the rate of heterosexual HIV transmission has been increasing in the past decade, in contrast with the overall decreasing trend in HIV transmission through sexual contact between men.

National surveillance for newly diagnosed HIV infection indicates that by December 1994 exposure to HIV was attributed to heterosexual contact in 7 per cent of cases. Information on sexual partners was unavailable for most cases. In those for which it was available, over half were in people who were either from countries where HIV is transmitted primarily by heterosexual contact (in sub-Saharan Africa and southern Asia) or sexual partners of people from these countries.

Overall, there has been a steady increase in the number of new HIV diagnoses in women who have become infected through heterosexual contact, from 10 in 1985 to 30 in 1988 and 52 in 1994.

There may have been some overcounting of diagnosed HIV infection attributed to heterosexual contact because of the unwillingness of some people, particularly men, to acknowledge other sources of exposure to HIV. Follow-up of cases of HIV infection in 1994 showed that most diagnosing doctors were satisfied with patient reports of exposure to HIV for cases attributed to heterosexual contact in women but were less satisfied with patient reports for cases in men attributed to heterosexual contact.

Among AIDS cases, exposure to HIV was attributed to heterosexual contact for less than 4 per cent of the cumulative number of AIDS diagnoses. Back projection from AIDS cases, however, suggests that there was an increase in

## POSITIVE WOMEN

Of the nearly 14 500 people infected with HIV in Australia in the past 10 years, only about 4 per cent have been women, a low statistic that many claim has marginalised and disadvantaged HIV-positive women.

Vivienne Munro is one of these women; she has been living with HIV for the past 10 years and keeps close contact with as many as possible of the 883 known positive women throughout Australia through formal and informal networks developed through AIDS councils and by the women themselves.

'In statistical terms we are a low priority for transmission of HIV in Australia, but what the authorities overlook is that while other methods of transmission have plateaued or declined, heterosexual transmission has consistently risen,' Vivienne said.

Vivienne is passionate about the need for more education and information for women about the risks of contracting HIV through unsafe heterosexual sex.

'Research shows that young women know about HIV/AIDS but find it very difficult to put safe sex into practice,' Vivienne said.

'It could and it does, and the surveillance figures show it is increasing, however slowly. Do we need a huge increase in heterosexual transmission before people wake up to this?' she said.

Vivienne discovered she was HIV-positive only a week after the birth of her second child.

'It was 10 years ago and my husband had been sick for some time but the doctors didn't know what was wrong with him. By the time they diagnosed HIV, there was a desperate race to see if I had seroconverted also. In those days you had to wait at least two weeks for test results, but eventually they found I was positive and I became the first known HIV-positive woman in Australia to give birth to a child with a negative status.'

After a year and a half of testing and retesting, it is clear that her son is HIV antibody negative, but not all children born to positive women are as fortunate.

In those early years of the epidemic, Vivienne experienced the harsh reality of isolation and lack of support services for positive women.

'We couldn't tell anyone about our positive status—it was at the time when little Eve Van Grafhorst was hounded out of her day care centre and eventually out of Australia because she was HIV positive. People didn't understand the virus and didn't know how to react.'

In 1989 Vivienne heard a radio program where a call was made for positive women to respond and she went along to the first meeting: 'There were seven women at that meeting, but this support set me on the path to what is now my life's work—bringing positive women into a national network of sharing and support. The Positive Women's Network also plays a vital role in giving women a voice in the management of a predominately male disease.'

heterosexually acquired HIV infection, at least among women, in the latter part of the 1980s.

Because of the restriction on eligibility for donating blood, blood donors constitute a population in which heterosexual contact is theoretically the only potential source of exposure to HIV, even though the donors may not be representative of the heterosexually active population as a whole. The prevalence of diagnosed HIV infection was less than 0.8 per 100 000 donations and remained low throughout the period 1985 to 1994. Of the 72 cases of diagnosed HIV infection in blood donors, 32 were attributed to heterosexual contact, but people with HIV infection who have donated blood may have been unwilling to report sources of exposure to HIV other than heterosexual contact. The incidence of new HIV infection in blood donors who made two or more donations was also very low from 1985 to 1994. And HIV prevalence was very low (0.01 per cent) among Defence Force entrants.

Surveillance for HIV infection among patients attending STD clinics has provided an indication of the extent of HIV infection in people who may be considered to be at a higher risk of HIV infection compared with the wider population. In 1992 to 1994 the prevalence of HIV in people who reported their only potential exposure to HIV as heterosexual contact was less than 0.1 per cent in both men and women. Around 65 per cent of heterosexual clients were tested for HIV antibodies.

In unlinked anonymous studies of HIV seroprevalence in pregnant women HIV prevalence was zero in a study of 10 000 women in 1988–89; it was 0.05 per cent in surveys in 1989–90 and 1991–92. Recent estimates of the prevalence of HIV infection in pregnant women based on back projection of AIDS diagnoses in children with perinatal HIV infection suggest an increase in prevalence from 0.004 per cent in 1983–85 to between 0.009 and 0.02 per cent in 1992–94. HIV prevalence in the estimated 50 000 pregnant women who were tested in 1994 was around 0.05 per cent. Overall, to the end of 1994 around 90 women with HIV infection were known to have had live births in Australia and 40 of their children had acquired HIV vertically.

HIV prevalence among pregnant women in the range 0.01 per cent to 0.05 per cent is similar to rates reported from several northern European countries but much lower than rates reported from southern Europe and the United States (see Table 2.17).

A number of surveys of heterosexual behaviour have provided an indication of time trends during the HIV epidemic. Among sexually active Australians in 1986 aged between 16 and 24 years, approximately 26 per cent of men and 17 per cent of women reported having changed their sexual behaviour in response to the epidemic. By 1995 the comparable figures were 35 and 38 per cent. The figures for the 35–44-year age group were lower, rising to only 13 per cent of men and 8 per cent of women in 1995. Among sexually active people who are

single, in 1995 the percentage of the 16–24 age group reporting having changed their sexual behaviour in response to the epidemic is 38 per cent for men and 49 per cent for women, and for the 35–44 age group 45 per cent and 31 per cent respectively.

In 1986, 11 per cent of single sexually active 16–24-year-old men reported always using condoms. By 1995 this had risen to 28 per cent. The comparable figures for the 35–44 age group are 8 per cent and 21 per cent. While data for women from these two years cannot be compared, 1991 data suggest that 46 per cent of 16–19-year-old women and 37 per cent of 20–24-year-old women were always using condoms for sex with casual partners and that the equivalent rates for sex with regular partners were 28 per cent and 9 per cent.

These data suggest an overall increase of between two and three times in the rate of always using condoms among single sexually active people between 1986 and 1995. Rates of increase consistent with this can also be derived from studies of university undergraduates between 1988 and 1994.

**Table 2.17 HIV prevalence in pregnant women and newborns, selected countries, 1991 to 1993**

Country	Year	Annual number of births ('000s)	Proportion tested (%)	HIV prevalence (per 1000)
Unlinked anonymous testing—pregnant women				
Finland	1993	64	100	0.08
France				
South-east	1992	11	97	4.23
Paris area	1992	11	97	5.56
United States	1993	-	-	1.7
Unlinked anonymous testing—newborns				
Germany				
Berlin	1993	27	99	0.58
Lower Saxony	1993	68	99	0.16
Italy	1993	162	100	0.96
UK				
Inner London	1993	34	99	2.58
Outer London	1993	47	99	0.88
Scotland	1993	64	100	0.28
Voluntary testing—pregnant women				
The Netherlands				
Amsterdam	1991	7	>90	1.09
Norway	1993	71	96	0.00
Sweden	1993	113	97	0.09

Source: NCHECR (1995).

# Australia's response to the HIV/AIDS epidemic

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Australia's response to the HIV/AIDS epidemic has been cooperative, pragmatic and rapid. Traditional public health approaches have been redefined, and our response has evolved as understanding of the epidemiology of HIV/AIDS has increased. Australia's response has been guided by the resolve to control the spread of HIV, to minimise its impact on people already affected, and to influence the way people think and feel about the sensitive questions raised by the epidemic.

## 3.1 HIV/AIDS IN AUSTRALIA, 1982 TO 1989

The cornerstone of Australia's response to HIV/AIDS has been a 'partnership' between the affected communities, governments at all levels, and medical, scientific and health care professionals. This partnership was forged in the early days of the epidemic.

The first cases of AIDS were reported in the United States. The first person with AIDS in Australia was diagnosed in late 1982 in Sydney, 18 months after the first case reports from the United States.

During 1983 and 1984 there were a number of disparate initiatives in response to the problem. Gay organisations disseminated information about HIV/AIDS and developed education programs. Education programs were developed by people affected with haemophilia, by sex workers, and by some drug services. In the government sector, efforts were made to secure the blood supply. The National Health and Medical Research Council established a medical working party on AIDS. State and Territory governments also funded some programs.

In late 1984 a National AIDS Task Force was established in response to increasing concern about the potential spread of the epidemic. The Task Force reported to the Australian Health Ministers Advisory Council and replaced the National Health and Medical Research Council working party. It guided the efforts of the medical and scientific community. A ministerial advisory committee, the National Advisory Committee on AIDS (NACAIDS) was established with community representation to advise on educational, social and legal issues.

In May 1985 the Australian Health Ministers' Conference endorsed the National Health Strategy for AIDS Control, which provided national

## RECIPIENTS OF BLOOD HARD HIT BY HIV

In 1984 a small volunteer group called the Australian Federation of Haemophilia was thrust into the national limelight when HIV/AIDS was found in Australia because of the total dependence its members had on treatment products made from blood plasma.

'Most of the 1500 people with haemophilia in Australia would have regular treatments which involved exposure to 2000–3000 blood donors for each treatment,' according to Jenny Ross, the Executive Director of Haemophilia Foundation Australia, as the group is now known. 'For severe haemophilia, people would have that exposure two or three times a week, so you can see why, of our group, 30 per cent became infected with HIV back in those early days of the epidemic,' she said.

Jenny said the Federal Government's first response to HIV infection in the haemophilia group was to allot \$10 000 for people with haemophilia to be tested for HIV. 'But they let people know by newspaper articles. Can you imagine how it was? People out there with haemophilia being told in one hit, through a newspaper, that they may be infected with HIV,' she said. 'What they really wanted was some information. It was an appalling time for us all.'

Over the next two or three months most people were tested and there was a repeat test to confirm the result six months later. 'Percentage-wise, our membership was the largest group of people to be infected with HIV,' Jenny said. 'Of all those infected with HIV, a third have died, a third are ill, and a third are very well.'

Jenny admitted there were some concerns about her members who were infected with HIV being lumped into 'at risk' groups like gay men and injecting drug users. 'We represent a very wide range of people, mostly families, and it was difficult for our people to deal with the discrimination they suffered,' Jenny said. 'In addition, services were geared more to the larger affected communities. For example, it was not uncommon in some areas for a mother wanting her 12-year-old child monitored to have to go to an STD clinic for adequate HIV/AIDS treatment.'

Jenny recalled that in November 1984 the Donor Declaration Form became available at all blood banks and people wishing to donate blood needed to fill one of these out. 'They were obviously very effective in discouraging people who may have been at risk of HIV infection from giving blood—the blood banks were shocked at the number of people who pulled out of the service. The form appeared to be very effective: when the actual antibody test came onto the market and all new blood donations were screened for HIV, they didn't find any additional cases of infected blood,' she said.

Although people with haemophilia are very small in number, Jenny feels there is no room for complacency about educating them about HIV/AIDS because there is still the threat of infected people passing the virus onto their sexual partners.

'It's difficult for people to practice safe sex every time and there is an enormous desire by our couples to have children, despite the problems,' she said. 'In the US people with haemophilia have a higher birth rate than the population average and so we are fearful that we could see a new wave of transmission to partners. We are working hard to minimise that,' she said.

leadership on HIV/AIDS matters and showed the political will and the strong government commitment to tackle the difficult problems raised by the epidemic.

Between 1984 and 1985 the Commonwealth began to directly fund community-based organisations and provide grants to State and Territory governments.

In 1985 a test for HIV became available. Australia became one of the first countries to have universal blood donor screening and accessible testing sites were made available free of charge to encourage testing.

During the mid-1980s there was a period of intense debate about testing strategies and the importance of persuasive and meaningful education and prevention programs. Political consensus on appropriate education and testing strategies developed during this time. By 1987 needle exchange programs had begun. Concern about the spread of the infection among heterosexuals in 1987 led to a national media campaign to raise general community awareness. NACAIDS, State and Territory health authorities, and community-based AIDS councils were all involved in these initiatives.

Between 1984 and 1988 the infrastructure necessary for a cohesive national response was developed, with the Commonwealth providing funding to key organisations.

The Australian Federation of AIDS Organisations (AFAO) was established in 1985 to represent AIDS councils at the national level. Haemophilia Foundation Australia represented haemophilia support groups. By 1988 the Australian Intravenous League, the Scarlet Alliance (representing sex workers) and the National Association of People Living with AIDS were affiliated with AFAO.

The Intergovernmental Committee on AIDS (IGCA) was established as a sub-committee of the Australian Health Ministers Advisory Council to provide a forum for regular Commonwealth–State liaison on policy, finance, programs and activities connected with HIV/AIDS. The States and Territories established their own HIV/AIDS committees to help with policy development.

The Parliamentary Liaison Group provided a mechanism to inform members of the Commonwealth Parliament about the latest HIV-related developments; it remains an important non-partisan forum for policy discussion.

In 1988 the Australian National Council on AIDS (ANCA) replaced NACAIDS and the National AIDS Taskforce. The Council is a ministerial advisory committee with representation from medical and scientific bodies and the community. The introduction of the Commonwealth AIDS Research Grants Program was a response to the need for scientific information to inform the national response and provided designated funding for AIDS research. Under the Program national research centres in virology, epidemiology and clinical medicine, and social and behavioural science were established.

In the 1987–88 Federal Budget there was a significant increase in funding for HIV/AIDS. Allocations were made for both education and prevention and treatment and care programs. At the end of 1988 a policy discussion paper, *AIDS: a time to care, a time to act*, was tabled in the Commonwealth Parliament and all State and Territory parliaments. During 1989 this paper was further developed through extensive national consultation and from it the first National HIV/AIDS Strategy was formed.

### **3.2 THE NATIONAL HIV/AIDS STRATEGY, 1989 TO 1995**

The first National HIV/AIDS Strategy provided a framework for an integrated response to the epidemic and a plan for action across a range of policy and program areas. It was supported by four years of funding. An important element of the Strategy was the continuing partnership between the affected community, government, and the scientific, medical and health care professions. The Strategy had two goals:

- to eliminate transmission of the human immunodeficiency virus (HIV); and
- to minimise the personal and social impact of HIV infection. (Commonwealth of Australia 1989, p. 23)

The Strategy rested on a set of guiding principles, which were a practical expression of the broad principles for health promotion contained within the 1986 Ottawa Charter. They also reflected the Commonwealth's social justice principles, emphasising access, equity, participation and equality for individuals and a client focus. The guiding principles, which have since been adopted by other countries, are as follows:

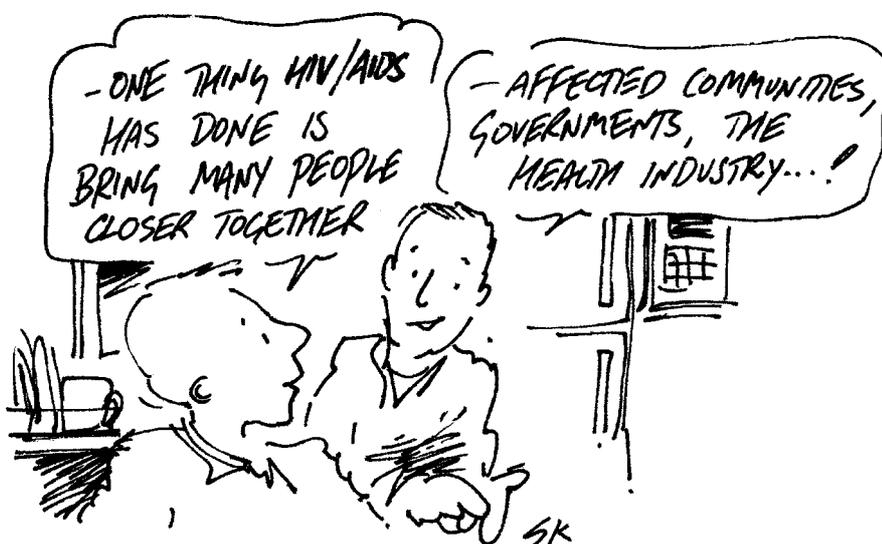
- Transmission of HIV is preventable through changes in individual behaviours. Education and prevention programs are necessary to bring about such changes.
- Each person must accept responsibility for preventing themselves becoming infected and for preventing further transmission of the virus.
- The community as a whole has the right to appropriate protection against infection.
- The law should complement and assist education and other public health measures.
- Elimination of discrimination against HIV positive people and protection of human rights of HIV positive people.
- Public health objectives will be most effectively realised if the cooperation of people with HIV infection and those most at risk is maintained.
- Specific informed consent should be obtained before any test is performed to diagnose a person's HIV infection

status. The results should remain confidential, and appropriate pre- and post-test counselling should be provided.

- People infected with HIV retain the right to participate in the community without discrimination, and have the same rights to comprehensive and appropriate health care, income support and community services as other members of the community.
- Professional care-givers have a duty to care for infected individuals; governments, employers, and unions have a responsibility to provide working conditions and training programs which minimise the risk of occupational transmission.
- Research into the epidemic is essential to the management of the epidemic. Strategies must be guided by up-to-date knowledge of the epidemiology and mechanisms of pathogenesis. (Commonwealth of Australia 1989, p. 24)

The first Strategy was evaluated in 1992 and as a result the approaches and programs used were fine-tuned. By 1993 the epidemic appeared to have stabilised—there were indications of a decrease in the incidence of new infections, which were predominantly in men who have sex with other men. At the same time there was a continuing increase in the incidence of AIDS among people already infected with HIV.

The National HIV/AIDS Strategy 1993–94 to 1995–96 incorporated a number of the evaluation findings and consolidated the approach of the first Strategy. A national target was set 'to reduce the incidence of new HIV infections in Australia to an annual rate of no more than 2 persons per 100 000 by the year 2000' (Commonwealth of Australia 1993a, p. 9). The two main challenges in the



second decade of the epidemic are halting the spread of the infection through sustained behaviour change and providing support to those already infected.

The second Strategy supported the change in emphasis from Commonwealth to State and Territory responsibility for direct program planning and delivery to minimise duplication and provide greater local flexibility. The Commonwealth AIDS Prevention and Education Program and the Commonwealth AIDS Workforce Information Standards and Exchange Program were brought to an end and the HIV Study Grants Program was moved to the Matched Funding Program.

Among the initiatives in the second Strategy have been a National Priorities Program administered by the Commonwealth, a Commonwealth Special Funding Program established to deal with HIV/AIDS matters as they affect Aboriginal and Torres Strait Islander people, and the transfer to the general blood transfusion service funding program of responsibility for funding HIV screening in blood transfusion services.

The Strategy has four programs to guide implementation: the Education and Prevention Program, the Treatment and Care Program, the Research Program, and the International Assistance and Cooperation Program. The States and Territories have an important part to play in achieving the objectives of the Education and Prevention and Treatment and Care Programs. The Commonwealth supports this through the provision of funding under the cost-sharing Matched Funding Program. The Commonwealth has responsibilities across all four Programs (Commonwealth of Australia 1993a, pp. 18–33).

The Education and Prevention Program has two broad aims:

to increase awareness of HIV/AIDS issues within the Australian community and to promote the development of community norms within populations at risk which support the establishment and maintenance of safe behaviours. This will be achieved through providing an appropriate range of public education initiatives and enabling individuals to assess their own risk and to make decisions about their behaviour.

The Treatment and Care Program has the following aim:

to improve the quality of the lives of those people living with HIV/AIDS through the provision of high quality, accessible and timely treatment, care, counselling and support in a cost effective manner.

The Research Program has two broad aims:

to increase knowledge of ways to eliminate or limit the spread of HIV infection and to reduce the harm to individuals and the community resulting from HIV infection through supporting a comprehensive research program and ensuring research results are translated into practice.

The International Assistance and Cooperation Program has the following aim:

to contribute to limiting the incidence and impact of HIV/AIDS globally with a particular focus on the Asia/Pacific region through participating in international policy development and implementation and assisting in policy and program development at a country level, drawing on the broad range of expertise, commodities and services available in Australia which are appropriate to the needs of developing countries.

### **3.3 ROLES AND RESPONSIBILITIES**

Each member of the partnership has distinct roles and responsibilities. The Commonwealth Government's role is to provide leadership in matters of national importance, to manage public education programs and the national HIV/AIDS Research Program, and to coordinate and monitor programs and activities on a national basis. It also has responsibility, either direct or shared, for HIV/AIDS in diverse areas ranging from immigration to superannuation and insurance. Consultation and cooperation are an important part of the Commonwealth's role. The supporting infrastructure is ANCA, the IGCA, the Parliamentary Liaison Group, the AIDS/Communicable Diseases Branch of the Commonwealth Department of Human Services and Health, and the Commonwealth AIDS Research Grants Program.

The States and Territories have responsibility to provide leadership at the level of their jurisdiction. They are responsible for the planning, funding, delivery, and monitoring and evaluation of education, prevention, treatment and care services provided through the health care system. They are also responsible for service provision and policy and legislation in related areas. Among the supporting infrastructure are the IGCA, State and Territory health departments, and State and Territory ministerial advisory committees.

Non-government organisations and volunteers play a vital part, providing peer education, information and counselling, and support and care for and by HIV-infected people and their partners, families and friends. This is accomplished by networks of volunteers and staff. They also have an important role in advocacy and the development of policies and programs. Among the supporting infrastructure are Haemophilia Foundation Australia, and AFAO and its affiliates the Australian Intravenous League, the Scarlet Alliance, the National Association of People Living with AIDS (NAPWA), and State and Territory AIDS councils.

Medical, scientific and health care professionals play a very important part, too—in the delivery of treatment and care services and in training, research and policy advice. The advisory role is facilitated by the inclusion of experts on ANCA and by direct consultation with the Commonwealth. Among the supporting infrastructure are professional organisations such as the Australian Medical Association, the Australasian Society for HIV Medicine, the

Australasian College of Venereologists, the Royal Australian College of General Practitioners and the Australian Nursing Federation.

Local government also has an important role, providing local services such as community nursing, supporting community-based organisations, facilitating education and prevention programs, and organising waste disposal programs.

### **3.4 FINANCING AND ACCOUNTABILITY**

#### **3.4.1 Expenditure**

The National HIV/AIDS Strategy 1993–94 to 1995–96 is financed through the following programs:

- the Matched Funding Program
- the Special Funding Program
- Medicare Hospital Funding Grants for AIDS
- the National Education Program
- the National Priorities Program
- the Commonwealth AIDS Research Grants Program
- the Support for National Community-based Organisations Program.

The first three programs involve Commonwealth grants to State and Territory governments; the remaining four are financed and administered by the Commonwealth.

Table 3.1 shows expenditure by the Commonwealth for the first two years of the Strategy. The total expenditure for 1993–94 was \$100 492 000 for 1994–95 it was \$103 408 000. The indexed allocation for 1995–96 is \$118 339 000. The largest single area of expenditure is the Commonwealth's contribution to the hospital inpatient care of people with AIDS.

Each of the funding programs has a different relationship to the four implementation programs. For example, the Matched Funding Program funds Education and Prevention, Treatment and Care, and some research. The Commonwealth AIDS Research Grants Program funds only research. Separating expenditure into the four implementation programs is difficult. Many projects funded through the Matched Funding and Special Funding Programs provide a range of services that cannot be neatly divided into implementation programs. This should be borne in mind when considering the allocations shown in Table 3.2. It is obvious, however, that Treatment and Care consumes by far the greatest share of HIV/AIDS resources.

**Table 3.1 Total Commonwealth-only allocations and expenditure on National HIV/AIDS Strategy 1993-94 to 1995-96 to each program area**

(\$'000)

Programs/funds	1993-94			1994-95				1995-96	
	Allocation	1993-94 expend.	1994-95 expend.	Total expend.	Indexed allocation	1994-95 expend.	1995-96 carry-over	Total expend.	Indexed allocation
<b>Programs</b>									
CARG	13 186	12 220	850	13 070	13 529	13 044		13 044	13 996
National Education Program	4 875	2 446	2 520	4 966	4 386	3 082	1 160	4 242	4 537
Support for national community-based organisations	670	569		569	687	687		687	711
Support for national advisory committees	350	235		235	359	374		374	371
Evaluation	300	47		47	513	550	150	700	531
National Priorities Program	1 300	960	680	1 640	1 702	1 100	777	1 877	1 923
International Program	300	289		289	350	314		314	200
<b>Total</b>	<b>20 981</b>	<b>16 766</b>	<b>4 050</b>	<b>20 816</b>	<b>21 527</b>	<b>19 151</b>	<b>2 087</b>	<b>21 238</b>	<b>22 269</b>
<b>Funds to States and Territories</b>									
Matched Funding Program	23 876	23 876		23 876	24 530	24 386		24 386	25 306
Special Funding Program	3 000	1 862	1 138	3 000	3 084	3 084		3 084	3 164
Medicare Hospital Funding Grants for AIDS		52 800		52 800		54 700		54 700	67 600
<b>Total</b>				<b>79 676</b>				<b>82 170</b>	<b>96 070</b>
<b>Total expenditure</b>				<b>100 492</b>				<b>103 408</b>	<b>118 339</b>

Source: Commonwealth of Australia (1995).

**Table 3.2 Total Commonwealth-only allocations on the National HIV/AIDS Strategy 1993–94 to 1994–95 to each implementation program**

(\$'000)

	1993–94					1994–95						
	Education & Prevention	Treatment & Care <sup>a</sup>	Research	International <sup>b</sup>	Other <sup>c</sup>	Total expend.	Education & Prevention	Treatment & Care <sup>a</sup>	Research	International <sup>b</sup>	Other <sup>c</sup>	Total expend.
<b>Programs</b>												
CARG			13 070			13 070			13 044			13 044
National Education Program	4 966					4 966	4 242					4 242
Support for national community-based organisations					569	569					687	687
Support for national advisory committees					235	235					374	374
Evaluation					47	47					700	700
National Priorities Program	1 341	99			200	1 640	1 523	30	35		289	1 877
International Program				289		289				314		314
<b>Total</b>	<b>6 307</b>	<b>99</b>	<b>13 070</b>	<b>289</b>	<b>1 051</b>	<b>20 816</b>	<b>5 765</b>	<b>30</b>	<b>13 079</b>	<b>314</b>	<b>2 050</b>	<b>21 238</b>
<b>Funds to States and Territories</b>												
Matched Funding Program <sup>d</sup>	8 187	7 997	451		7 240	23 876	8 362	8 168	461		7 395	24 386
Special Funding Program <sup>e</sup>	2 024	150			826	3 000	2 080	155			849	3 084
Medicare Hospital Funding Grants for AIDS		52 800				52 800		54 700				54 700
<b>Total</b>	<b>10 211</b>	<b>60 947</b>	<b>451</b>		<b>8 066</b>	<b>79 676</b>	<b>10 442</b>	<b>63 023</b>	<b>461</b>		<b>8 244</b>	<b>82 170</b>
<b>Total expenditure</b>	<b>16 518</b>	<b>61 046</b>	<b>13 521</b>	<b>289</b>	<b>9 117</b>	<b>100 492</b>	<b>16 207</b>	<b>63 053</b>	<b>13 540</b>	<b>314</b>	<b>10 294</b>	<b>103 408</b>

## Notes:

- Only includes treatment and care funding under the Strategy. Other Commonwealth expenditure includes Medicare rebates for consultations with medical practitioners and subsidies for pharmaceuticals. An estimate of the total cost of treatment and care is in Section 5.3.1.
- Department of Human Services and Health expenditure only. Expenditure by AusAID on HIV/AIDS projects is reported in Chapter 7.
- 'Other' for SFP and MFP includes training, testing and evaluation.
- Although MFP education and prevention allocation is less than the required 40 per cent, this does not mean the requirement is not being met by the States and Territories because State and Territory contributions exceed the minimum MFP requirements. Combined Commonwealth, State and Territory expenditure on education and prevention is in excess of 40 per cent. MFP for 1994–95 is an estimate only based on percentage expenditure for 1993–94.
- SFP for 1993–94 and 1994–95 are estimates only based on percentage allocations from project register returns for 1993–94. SFP 1993–94 is missing data for some States and Territories. 'Other' could be overestimated for 1994–95 due to high establishment costs of projects in their first year.

Source: Commonwealth of Australia (1995).

### 3.4.2 The Matched Funding Program

Under the Matched Funding Program (MFP) the Commonwealth allocates to the States and Territories funds that are matched on a dollar-for-dollar basis. Services are provided by State and Territory government organisations such as hospitals and community health centres and by non-government organisations such as AIDS councils. Implementation of the MFP follows the guiding principles and funding arrangements set out in the second Strategy.

Table 3.3 shows the Commonwealth's allocation of MFP funds to the States and Territories for 1993–94 to 1995–96. The States and Territories can, and do, allocate funds in excess of the matching requirements of the Strategy. These are reported annually by the IGCA.

**Table 3.3 Total Commonwealth-only Matched Funding Program expenditure and allocation by States and Territories, 1993–94 to 1995–96**

(\$'000)

State/Territory	Total expenditure 1993–94	Indexed allocation 1994–95	Total expenditure 1994–95	Indexed allocation 1995–96
NSW	10 573	10 841	10 841	11 206
Vic	4 928	5 015	4 890	5 179
Qld	3 137	3 284	3 284	3 388
WA	1 870	1 941	1 941	1 999
SA	1 648	1 700	1 700	1 750
Tas	640	645	645	659
NT	567	582	563	593
ACT	513	522	522	531
Total	23 876	24 530	24 386	25 306

Source: Commonwealth of Australia (1995).

Under the current funding formula each State and Territory receives a base grant of \$250 000. The remaining funds are split between the States and Territories thus:

- 5 per cent based on the Aboriginal and Torres Strait Islander population;
- 45 per cent based on the total population;
- 50 per cent based on the number of people living with AIDS.

The States and Territories submit their proposed annual budget for the MFP to the Department of Human Services and Health, using categories developed by the IGCA. The budgets must be accepted by the Commonwealth before a formal offer of funds is made for the year. An annual statement of expenditure and a certificate of compliance are required within five months of the end of the financial year. A minimum of 40 per cent of the total matched funds must be allocated to education and prevention.

At the end of each financial year the States and Territories are required to supply project summary reports on all projects funded under the MFP. The Commonwealth maintains a register of projects and data are analysed within the AIDS/Communicable Diseases Branch of the Department, to assess the extent to which cost-shared activities are consistent with the matched funding arrangements. The IGCA reports on this annually.

### **3.4.3 The Special Funding Program**

The Special Funding Program (SFP) is designed to improve HIV/AIDS/STD services for Aboriginal and Torres Strait Islander communities. Funds are offered to the States and Territories according to the size of their Aboriginal and Torres Strait Islander populations. The States and Territories have been required to keep MFP expenditure on services for Aboriginal and Torres Strait Islander people at a level equal to or greater than that reached prior to the introduction of the SFP.

Under the SFP guidelines State and Territory health departments are required to develop strategic plans for the use of Program funds and to consult with Aboriginal and Torres Strait Islander people. The Commonwealth Minister for Health is responsible for approving expenditures under the SFP. At the end of each financial year the States and Territories are required to supply project summary reports on all projects funded under the SFP. The reporting mechanism is the same as for the MFP.

### **3.4.4 Medicare Hospital Funding Grants for AIDS**

The Medicare Hospital Funding Grants (HFGs) for AIDS contribute to meeting the cost of all hospital services for the care of people with AIDS. The level of funding to each State and Territory is determined according to Schedule G of the Medicare Agreement 1993–98. It takes into account changes in the number of AIDS cases on 1 November each year, any changes in the total population, and changes in the Medicare Index. The Medicare Index reflects changes in the Consumer Price Index and changes in hospital awards. No specific planning, reporting or accountability is required by the Commonwealth in relation to the HFGs for AIDS.

### **3.4.5 The National Education Program and the National Priorities Program**

The National Education Program (NEP) and National Priorities Program (NPP) are funded by the Commonwealth and administered through the AIDS/Communicable Diseases Branch of the Department of Human Services and Health. The NEP is intended to provide an integrated approach to the Commonwealth's delivery of HIV/AIDS education programs. ANCA is responsible for determining broad priorities in accord with the priorities and objectives of the second Strategy. The Education and Prevention sub-committee

and the IGCA and the community sector are also seen as stakeholders.

The NPP is also administered by the AIDS/Communicable Diseases Branch. Its purpose is defined in the Strategy: 'Funding is allocated at the discretion of the Commonwealth in response to emerging issues and identified program gaps requiring collaborative national action' (Commonwealth of Australia 1993a, p. 42). To qualify for funding under the NPP, projects must have national significance and must not be able to be funded under any other element of the Strategy.

### **3.4.6 The Commonwealth AIDS Research Grants Program**

Under the second Strategy funding is provided for a coordinated program of research. Until 1994 responsibility for the allocation and administration of the research funds was held by the Commonwealth AIDS Research Grants Program, which is a sub-committee of the ANCA. Program responsibilities included allocating research funds in accordance with the Strategy and ensuring that funds were spent on the purposes for which they were allocated.

### **3.4.7 The International Assistance and Cooperation Program**

A small sub-unit of the AIDS/Communicable Diseases Branch is responsible for the Department of Human Services and Health's contribution to international efforts to respond to HIV/AIDS. The majority of the expenditure reported for the International Assistance and Cooperation Program in Tables 3.1 and 3.2 is to fund the secondment of an officer from the Branch to a position with the General Management Committee Task Force on HIV/AIDS Coordination at the Global Program on AIDS, a World Health Organisation instrumentality based in Geneva.

### **3.4.8 The Support for National Community-based Organisations Program**

The Commonwealth funds a program of national HIV/AIDS activities through two peak AIDS organisations: Haemophilia Foundation Australia and AFAO. Expenditure on this is reported in Tables 3.1 and 3.2. These organisations receive their core funding through the Commonwealth's Community Organisations Support Program.

In 1994–95 the Commonwealth also provided funding to NAPWA to facilitate communication between State and Territory groups of people living with HIV/AIDS.

### **3.4.9 Support for national HIV/AIDS committees**

Commonwealth funding is provided for the operation of ANCA, to provide stipends for council members and to support Commonwealth-hosted meetings of the IGCA and the Parliamentary Liaison Group. Expenditure on this activity is reported in Tables 3.1 and 3.2.

# Slowing the epidemic— the Education and Prevention Program

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## 4.1 INTRODUCTION

The Education and Prevention Program has been the cornerstone of the effort to limit the spread and impact of HIV/AIDS in Australia. The aim of the Program is to increase awareness of HIV/AIDS within the Australian community and promote within populations at risk community norms that establish and maintain safe behaviours. The Program has four main objectives:

- to improve knowledge of risk behaviours and skills in the assessment of risk;
- to facilitate and promote access to voluntary testing and preventive measures and programs;
- to help people living with HIV/AIDS make informed decisions about their health and treatment;
- to reduce myths, unnecessary fears and discrimination.

### 4.1.1 Program design

The Education and Prevention Program is both a product of and an influence on the wider social and cultural environment. For example, the mobilisation of gay men against HIV/AIDS built on the activism of gay men during the 1970s. This mobilisation has been instrumental in the organisation of the Australian response to HIV/AIDS. Further, the organisation of sex workers early in the epidemic, before the development of an HIV/AIDS strategy, meant that cooperative efforts with government were likely to be much more effective once they began. General community attitudes about public discussion of sexual matters have influenced the form and targeting of educational material. It has been argued that HIV/AIDS has accelerated a process of social change leading to more open public discussion of sexual behaviour. HIV/AIDS education programs are both cause and effect in this process.

The diversity of Australian culture and the plurality of values associated with the intimate behaviours related to the transmission of HIV make education and prevention a challenging task.

Within this context, the Education and Prevention Program has adopted a complex design, subdividing the population into multiple target groups that have different information needs and require different educational approaches.

The varied approaches are intended to have a cumulative effect through the complementary activity of national, State and Territory, and local agencies each working at a different level of generality and aiming at particular audiences.

In the second National HIV/AIDS Strategy it was stated that the Program should focus on HIV/AIDS in the broader sexual health context. This approach was considered particularly appropriate for people engaging in heterosexual and bisexual activity. Links with other related health education programs, especially drug and alcohol services, were also to be strengthened.

The Program also incorporates the principle that the design and delivery of education programs for the sub-groups most directly affected by HIV are best done at the community level and by members of targeted groups themselves in consultation with government funding bodies.

Implementation of these design principles in the second Strategy has produced a diversity in education and prevention activity—mass media campaigns, community development strategies, peer education activities, outreach to hard-to-reach groups (for example, homeless youth), needle and syringe distribution, condom provision at gay community events, free and confidential HIV testing and counselling, and the incorporation of HIV/AIDS education in the work of schools, primary health services, prisons, occupational health and safety programs and other community services. As well, the mainstream media are regarded as a critical educator of the general community and are therefore supplied with information by a number of agencies, including the AIDS/Communicable Diseases Branch of the Department and Human Services and Health and ANCA.

Figure 4.1 shows the components of the Program and the logic of their relationship to the Program's final outcome—the prevention of HIV transmission. Obviously, the effectiveness of the Program is influenced by the degree of support it receives from the broader legislative and social policy environment.

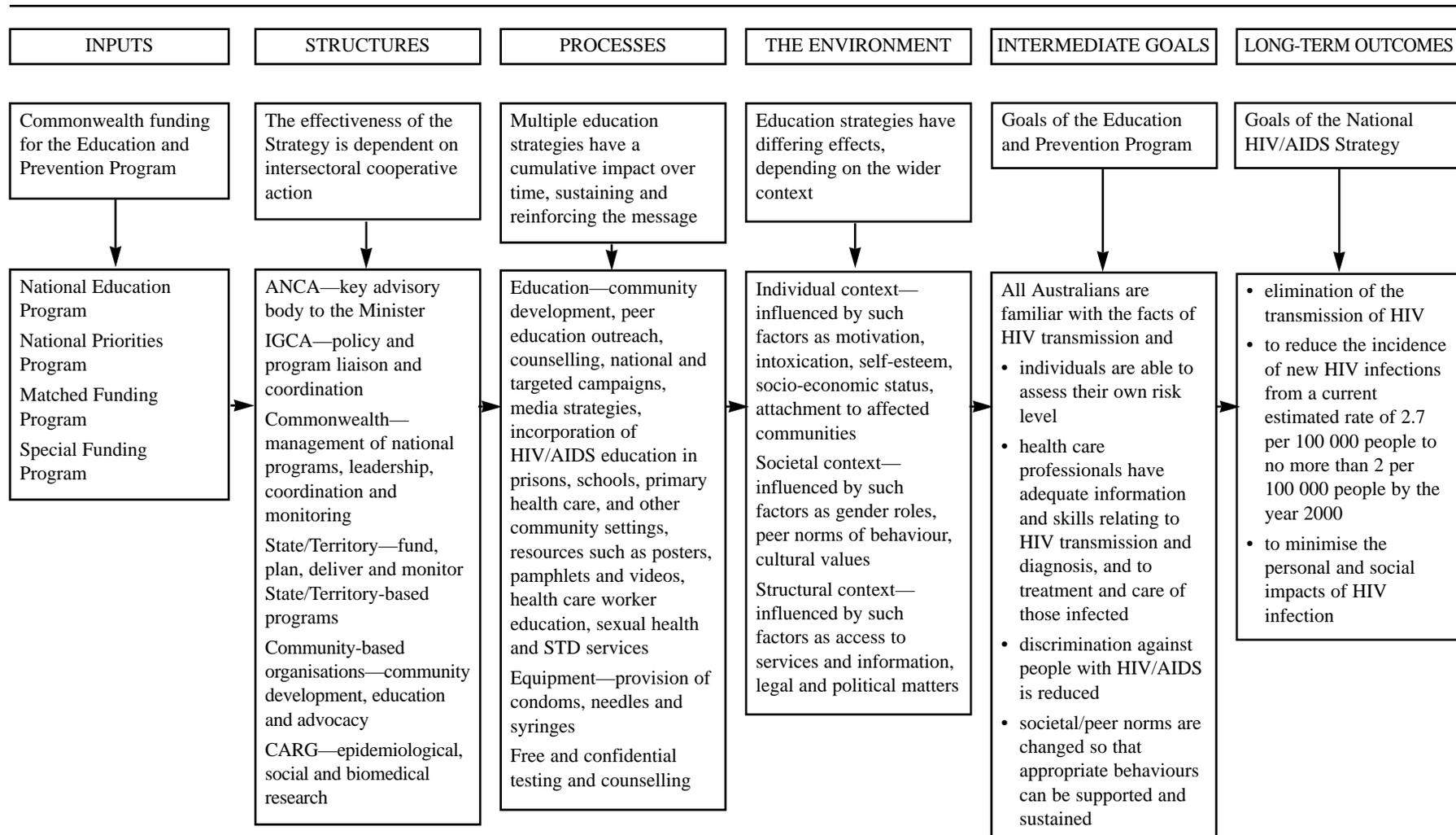
#### **4.1.2 Priorities for education and prevention: the target groups**

The main focus of the current Education and Prevention Program is people whose activities place them at greatest risk of infection and those already infected (Commonwealth of Australia 1993a, p. 21).

Five priority groups for the Program were identified through an understanding of the epidemiology of HIV/AIDS in Australia:

- homosexually active men—the group with the highest priority;
- injecting drug users and their sexual partners;
- Aboriginal and Torres Strait Islander people;
- people living with HIV/AIDS;

**Figure 4.1 The program logic**



Source: Commonwealth of Australia (1995)



- other priority groups—including sexually active young people (especially disadvantaged young people), prisoners (especially Aboriginal and Torres Strait Islander prisoners), sex workers and their clients, and women who have sex with gay or bisexual men or with male or female injecting drug users. Special consideration is also given to people who experience difficulty gaining access to the Program's services.

The priorities were not intended to dictate the extent to which funds were allocated to particular target groups or programs since this may vary according to the cost requirements of the particular program (Commonwealth of Australia 1993a, p. 21).

Two other broad priorities for education and prevention were identified:

- carers of people with HIV/AIDS—involving training of health care workers and volunteers, from basic understanding and knowledge to specialised skill development;
- general community education—including initiatives to help create a climate of understanding about HIV/AIDS and to inform people about its transmission. School-based HIV/AIDS education was considered to have the greatest potential to offer a comprehensive and efficient means of long-term access to the general community.

## 4.2 PROGRAM FUNDING

### 4.2.1 Overview

The Program is funded and delivered through the National Education Program, the National Priorities Program, the Matched Funding Program and the Special Funding Program. Table 4.1 shows expenditure for 1993–94 and 1994–95, by

funding program and primary target group. Details of actual expenditure are available only for the first year of the second Strategy. In 1993–94 expenditure was \$31.4 million; for 1994–95 the estimated expenditure was \$34.8 million. The major source of funding for education and prevention activity was the Matched Funding Program, which contributed 80 per cent of expenditure in 1993–94 and 74 per cent of estimated expenditure in 1994–95. The target group that attracted the largest share of funding was injecting drug users (27 per cent).

#### **4.2.2 The National Education Program**

The NEP is wholly funded and managed by the Commonwealth and is intended to provide an integrated approach to the Commonwealth's delivery of education and prevention services. Planning, priority setting, development and implementation take place in consultation with ANCA and the IGCA.

During the evaluation, criticism was voiced in a number of quarters that the NEP lacks strategic planning and is poorly coordinated with State and Territory projects.

The NEP has funded a diverse range of projects, including large campaigns such as the Travel Safe campaign, the anti-discrimination campaign, and a health monitoring and maintenance program for people living with HIV/AIDS. It has also funded numerous smaller projects such as those to counter discrimination in health care settings and developed educational resources for schools. A campaign directed at gay and other homosexually active men is currently being developed. These projects fit the NEP's brief. There have been criticisms of the lack of major initiatives for homosexually active men and injecting drug users in the first 18 months of the second HIV/AIDS Strategy. There have also been criticisms of the lack of strategic planning mechanisms and a clear process for determining priorities.

The absence of national campaigns directed at homosexually active men and injecting drug users is in keeping with the principles endorsed in the second National HIV/AIDS Strategy. As noted in Section 4.1.1, these principles stated that design and delivery of education programs for groups directly affected by HIV/AIDS is best done at the community level by members of the target group. There is now, however, a reconsideration of the role of national campaigns and their importance in relation to other education and prevention activities.

More attention should be given to establishing sound mechanisms for priority setting and resource allocation. And further thought should be given to the balance between campaigns and other models of educational practice as part of an overall strategic approach.

#### **4.2.3 The National Priorities Program**

The NPP is also wholly funded and managed by the Commonwealth. Its purpose is to enable the Commonwealth to respond to emerging problems or

**Table 4.1 Total Commonwealth and State and Territory funding for HIV/AIDS education and prevention programs, by primary target group and expenditure category, 1993–94 and 1994–95<sup>a</sup>**

(\$'000)

Primary target group	1993–94 <sup>b</sup>							1994–95 <sup>c</sup>					
	NEP	NPP	MFP	SFP	CAPE CAWISE <sup>d</sup>	Total	% of total funding	NEP	NPP	MFP	SFP	Total	% of total funding
Injecting drug users	9		8 504		13	8 526	27.14		133	8 686		8 819	25.31
Homosexually active men	38	96	2 867		93	3 094	9.85	333	342	2 928		3 603	10.34
General community	726		1 278		111	2 115	6.73	2 185		1 305		3 490	10.02
Sex workers		20	2 716		129	2 865	9.12		50	2 774		2 824	8.10
Youth	350		1 928			2 278	7.25	68		1 969		2 037	5.85
People living with AIDS	718	16	1 851		147	2 732	8.70	28	77	1 891		1 996	5.73
Aboriginal and Torres Strait Islander people	186	171	994	888	327	2 566	8.17	171	409	1 015	2 080	3 675	10.55
Health care workers	49	122	1 386		212	1 769	5.63	764		1 416		2 180	6.26
People with/at risk of an STD			1 650			1 650	5.25			1 685		1 685	4.84
Young heterosexuals	868	88			124	1 080	3.44	544	170	-		714	2.05
Women	20	136	135		49	340	1.08	85	151	138		374	1.07
Travellers	266		196			462	1.47	1 033		200		1 233	3.54
Non-English-speaking background	25		521		16	562	1.79	159	20	532		711	2.04
Corrective services			354		81	435	1.38			362		362	1.04
Administration	121					121	0.39	231		-		231	0.66
People with haemophilia			79			79	0.25			81		81	0.23
People with disabilities			78			78	0.25			80		80	0.23
Friends, family and carers			36		9	45	0.14			37		37	0.11
International		12				12	0.04		30			30	0.09
Emergency service workers						-	0.00					-	0.00
HIV/AIDS educators						-	0.00		60			60	0.17
Legal workers					6	6	0.02		39			39	0.11
TB/HIV						-	0.00					-	0.00
Education and prevention for staff and volunteers			210			210	0.67			214		214	0.62
Other			362		26	388	1.24			370		370	1.06
<b>Total</b>	<b>3 376</b>	<b>661</b>	<b>25 145</b>	<b>888</b>	<b>1 343</b>	<b>31 413</b>	<b>100.00</b>	<b>5 601</b>	<b>1 481</b>	<b>25 682</b>	<b>2 080</b>	<b>34 844</b>	<b>100.00</b>

a. This table provides an analysis by Primary Target Group and Expenditure Category. This is achieved by first apportioning all of the project costs to the Primary Target Group, and then apportioning these costs to each expenditure category identified by each project. In the project register the term Primary Target Group refers to the specific client group that is the primary focus of the project; the term Expenditure Category refers to each of the activities performed by the project.

b. Actual expenditure.

c. Figures for NEP and NPP are actual expenditure; MFP and SFP figures are estimated expenditure.

d. CAPE (Commonwealth AIDS Prevention and Education) and CAWISE (Commonwealth AIDS Workforce Information, Standards and Exchange) programs have ceased.

Funds to enable completion of existing projects in 1993–94 were made available in the second Strategy. In their place, States and Territories were offered increased funding.

Notes: SFP 1993–94 missing data for some States and Territories; means total funding under SFP is under-reported.

MFP 1993–94 missing data for some States and Territories. The project register was analysed by Primary Target Group of project and may under- or over-estimate the extent of service provision to each group.

SFP and MFP 1994–95 estimates only, based on percentage allocations for 1993–94; MFP is Commonwealth and State/Territory contribution.

'Young heterosexuals' includes figures for 'At-risk youth'; 'Youth' includes 'school-based education'; 'Young heterosexuals' includes work with IDUs and at-risk youth; 'General community' and 'Health care workers' include work on HIV/AIDS-related discrimination.

Source: Commonwealth of Australia (1995).

deficiencies in existing programs that require national action. There are no specific guidelines for the Program and funding is allocated at the discretion of the Commonwealth.

Over forty projects have been funded out of the NPP in the last two years. A number of these meet the Program's stated brief, including the Tri-state Program for Aboriginal communities, the development of an education strategy for gay men, the development of a comprehensive strategy for sexual health education for people from non-English-speaking backgrounds, and a legal education project. Some other projects appear to be inconsistent with the NPP's central purpose, but the Program's vague mandate does not lend itself to tight management or close evaluation.

There has been an inaccurate perception in the community that the NPP was designed to provide grants to meet special community or local needs. The lack of guidelines and the allocation of funds to projects that are not clearly related to the Program's central purpose have encouraged this perception. Accordingly, although the NPP has been successful in confronting a number of important emerging national problems, the criticism that it has lacked a clear process for establishing priorities and allocating resources is quite valid and should be redressed in a third Strategy.

#### **4.2.4 The Special Funding Program**

The SFP is designed to fund State and Territory Aboriginal and Torres Strait Islander HIV/AIDS/STD projects. The Program requires that the States and Territories allocate funding in keeping with Aboriginal and Torres Strait Islander strategic plans and in consultation with Aboriginal and Torres Strait Islander communities.

Of the \$3 million available under the SFP in 1993–94, only \$888 000 was spent on education and prevention, and in some jurisdictions much of this was spent on consultation and program development rather than actual education and prevention activities. Specific criticisms of the SFP included the lack of clarity in the guidelines for funding allocation and the fact that State and Territory strategic plans and consultation processes were in varying stages of development. Indeed, some jurisdictions' strategic plans were still being developed in August 1995. It is acknowledged that the diversity of Aboriginal and Torres Strait Islander communities and the often lengthy process necessary for effective consultation were frequently at odds with administrative deadlines required for funding allocation and use. The result, however, has been a 'scatter gun' approach and delays in establishing projects in 1993–94.

#### **4.2.5 The Matched Funding Program**

The MFP is the source of the largest amount of education and prevention funds. There has been almost a fourfold real increase in actual expenditure for education and prevention programs under the Program during the 10 years

since the start of the government response to the HIV epidemic in 1984–85. In spite of this, there has been a gradual decline in the proportion of total MFP funds spent on education and prevention, from 64 per cent in 1989–90 to 50 per cent in 1993–94. This is in line with the requirement that a minimum of 40 per cent of the MFP be devoted to the Education and Prevention Program. The gradual decline in the proportion of the allocation to education and prevention was anticipated in the National HIV/AIDS Strategy because of the increasing care and support needs of people living with HIV/AIDS.

Implementation of the MFP at the State and Territory level should be based on the pattern of the local epidemic and the priorities of the National HIV/AIDS Strategy. Table 4.2 shows that between 1989–90 and 1993–94 the ‘Other’ priority group—which includes the general community, health care workers and sex industry workers—consistently accounted for the largest proportion of funds expended on education and prevention. Although expenditure on these groups is important, the level of expenditure calls into question the planning and priority setting of the Program and supports the criticism that in some jurisdictions historic funding patterns have been maintained and there has not been an adequate response to priority groups or emerging needs.

**Table 4.2 Matched Funding Program expenditure on education and prevention, by primary target group, 1989–90 to 1993–94**

Primary target group	1989–90		1990–91		1991–92		1992–93		1993–94	
	\$'000	%	\$'000	%	\$'000	%	\$'000	%	\$'000	%
Aboriginal and Torres Strait Islander people	1 017	4.2	1 297	4.3	1 635	5.2	1 794	4.7	2 428	6.7
Homosexually active men	1 510	6.2	2 177	7.3	2 168	6.9	3 435	9.0	4 338	12.0
Injecting drug users	6 935	28.5	8 231	27.6	9 669	30.7	9 532	24.9	10 128	28.1
Others	14 887	61.1	18 159	60.8	17 976	57.2	23 526	61.4	19 156	53.1
Total	24 349	100.0	29 865	100.0	31 448	100.0	38 286	100.0	36 050	100.0

Note: Figures were calculated using a number of assumptions, among them the following:

- All activities in the project register were allocated into Education and Prevention, Treatment and Care, or Research.
- 80 per cent of all administration of AIDS councils/NGOs was allocated to Education and Prevention.
- 50 per cent of the AIDS component of mainstream health services was allocated to Education and Prevention.
- 95 per cent of funding for State and Territory administration was allocated to Education and Prevention.
- HIV Study Grants scheme was allocated to Education and Prevention.

As a result, total funding for Education and Prevention is much greater than that shown elsewhere in the report.

Source: Butler (1995a).

## 4.3 HOMOSEXUALLY ACTIVE MEN

### 4.3.1 Funding

Projects directed at homosexually active men have been funded through the NEP, the NPP and the MFP. Ten per cent of expenditure was on homosexually active men in 1993–94 and there has been a similar allocation in 1994–95 (see Table 4.1). There was an increase in the proportion of funds committed to

homosexually active men through the MFP in 1993–94 compared with previous years (see Table 4.2) (Butler 1995a). The fact that only a relatively small proportion of NEP and NPP funding was spent on homosexually active men in 1993–94 is a problem since this group is the highest priority group for the Education and Prevention Program. This problem has been redressed in the 1994–95 expenditure.

Of MFP expenditure directed at homosexually active men, 58 per cent was administered through non-government organisations (see Table 4.3). Projects carried out by State and Territory AIDS councils accounted for the majority of such expenditure. All AIDS councils ran projects to reinforce and maintain behaviour change among homosexually active men and to reach those who were new to the gay community, only occasionally in contact with the gay community, or have no identification with the gay community. Education strategies include peer education, outreach and telephone counselling. The majority of State and Territory government expenditure on homosexually active men under the MFP was for services delivered through sexual health centres. This reflects the move to provide HIV/AIDS education within a broader sexual health context. Homosexually active men are also found in other target groups, such as people living with HIV/AIDS, injecting drug users, youth and sex workers, and make use of services designed for these groups as well as those designed specifically for homosexually active men.

**Table 4.3 Education and prevention programs for homosexually active men, government and non-government services: Matched Funding Program by State and Territory, 1993–94**  
(\$'000)

State/Territory	Government services	Non-government services	Total
NSW	1 004	715	1 719
Vic	112	291	403
Qld	153	357	510
WA	10	145	155
SA	16	113	129
Tas	9	23	32
NT	5	77	82
ACT	–	81	81
Total	1 309	1 802	3 111

– Nil.

Notes: The project register was analysed for percentage of funding on the Target Group of homosexually active men. In the project register the term Target Group refers to each of the client groups that have been identified as beneficiaries of the outcomes flowing from the project. This table provides an analysis of Expenditure Category by Target Group. This is achieved by first apportioning project costs to the Expenditure Categories identified by each project and then apportioning the costs relating to education and prevention to the Target Groups identified as beneficiaries of each project. As a result, funding for this group is higher than that seen in Table 4.1 (MFP expenditure is \$2.87 million), which shows funding for homosexually active men as a primary target group by expenditure category only.

Source: Commonwealth of Australia (1995).

## GAY EDUCATION OVERHAUL

The first case of AIDS was diagnosed in Australia 13 years ago and education for gay men started about 11 years ago, but now that it appears AIDS is going to be here for ever for gay men many people are reassessing their responses to safe sex, according to Ross Duffin, project coordinator for a major federal government inquiry into HIV/AIDS education for gay men.

Ross said gay men are having to make some fundamental, long-term adjustments and there is a whole new generation of young gay men who were only 10 years old when HIV took hold in Australia.

‘So much has changed in the past decade,’ he said. ‘For example, 10 years ago we did not encourage antibody testing and the rule was “don’t ask, don’t tell”. In other words, assume everyone is HIV positive and practice safe sex always. That’s completely changed now as men prefer to tell every new partner their HIV status and, if practical, negotiate about safe sex; that is, whether or not to use a condom.

‘As educators we must acknowledge this is happening and address the issues of trust and honesty in relationships and set down some rules to deal with negotiated sex,’ he said.

Ross said his research is showing that the nature of gay men’s relationships is changing too. ‘Inevitably HIV/AIDS has had some long-term consequences on how gay men construct their lives and now we are paying a lot more attention to such things as relationships instead of sex for the sake of it.’

Ross said another major change in emphasis is that the gay community is acknowledging that stopping the spread of HIV is a shared responsibility, not just the responsibility of positive people.

‘The opportunity to use HIV-positive people who have only recently seroconverted to educate other gay men is also something we make use of more these days. For example, for a person who seroconverted because he thought withdrawal was a safe sexual practice, it is very powerful education for them to say to others, “I thought I knew everything, to my cost”.

Ross and his team have been compiling information for the report for the past five months. ‘We have consulted widely with gay men, doctors, nurses and others involved in HIV/AIDS and we have investigated issues such as alcohol and drug use, grief and loss, and contentious sexual concerns like oral sex and positive sex as they affect safe sexual practices.

‘We expect this comprehensive study of gay men’s behaviour to significantly influence the form in which HIV/AIDS gay education is undertaken into the next century,’ Ross said.

### **4.3.2 The efficiency of education and prevention programs for homosexually active men**

Economic analysis of education and prevention programs is important because it allows comparison of the cost of such programs with their outcomes or benefits. An economic analysis of aspects of the National HIV/AIDS Strategy was commissioned for the evaluation; the full report will be published as a separate document. The analysis in this section, and in Section 4.4.2, is a summary of the part of that report dealing with the Education and Prevention Program (Hurley, Becker & Butler 1995).

The commissioned analysis was restricted to the cost-effectiveness of education and prevention programs for homosexually active men because this group is the one in which most HIV infections have occurred and there are technical difficulties involved in applying the analysis to the smaller epidemics among other groups in Australia.

It is impossible to directly measure the number of HIV infections prevented as a result of government intervention through the Education and Prevention Program. But it is known that the incidence of HIV infection among homosexually active men has declined since 1984. It is reasonable to assume some of this decline is attributable to behaviour change that came about as a result of the Program. Estimates of this outcome were derived as follows.

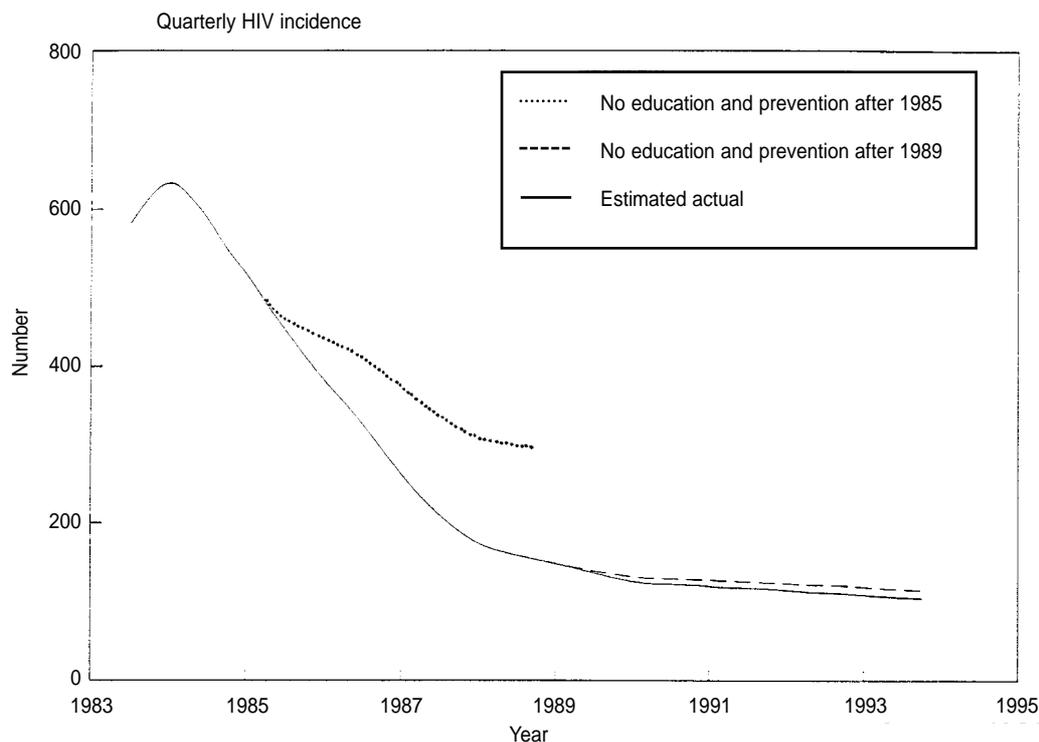
A mathematical model of the HIV epidemic was developed based on the estimated incidence of HIV obtained from back projection from the number of AIDS cases (see Section 2.2). This was done by making assumptions about the size of the homosexually active male population and adjusting the rate of transmission of HIV (or the proportion of sexual contacts that are infectious) within the population until the model replicated the best estimate of actual HIV incidence. The rate of transmission may have changed because of a change in the proportion of men engaging in high-risk behaviour resulting from an initial rapid spread of the infection among a high-risk-behaviour group whose members subsequently developed AIDS and died. The rate of transmission may also have changed because homosexually active men changed their sexual behaviour. On the basis of social research on change in high-risk sexual behaviour among homosexually active men over the course of the epidemic, it was assumed that one-quarter of the reduction in the transmission rate was due to a change in behaviour. The question of how much of this behaviour change should be attributed to the effect of education and prevention programs was resolved by taking three estimates. The best (or most efficient) case attributed 100 per cent of behaviour change to such programs. The worst case attributed only 10 per cent of behaviour change to such programs. The most plausible, or base case was to assume that 50 per cent of behaviour change derived from education and prevention programs.

Figure 4.2 compares the estimated actual incidence of HIV among homosexually active men with estimates of what the incidence would have been in the absence of education and prevention programs. These estimates were developed for two periods—between 1985 and 1989 and between 1989 and 1993. These periods correspond approximately with the beginning of organised education and prevention programs, including those funded by governments, until the first Strategy began in 1989, and with the duration of the first Strategy. It was not possible to model the period of the second Strategy because estimates of actual HIV incidence are too imprecise the closer we come to the present.

In the first period, 1985 to 1989, between 313 and 3850 infections were prevented by HIV/AIDS education and prevention programs for homosexually active men. In the second period these programs prevented between 23 and 146 infections.

To convert these estimates of the number of infections prevented into the number of years of life saved, it was assumed that a man infected with HIV at age 28 would die at age 40, and that in the absence of infection he would have died at age 75. Prevention of one HIV infection is therefore assumed to save 35 years of life, or 9.1 years when these are discounted at an annual rate of 5 per cent (a standard technique in economics for determining the present value of benefits that will occur in the future).

**Figure 4.2 Estimated actual HIV incidence and predicted HIV incidences assuming no education and prevention programs after 1985 and 1989**



Preventing an HIV infection results in a saving to the health system because of the treatment cost that is avoided. The estimated lifetime treatment cost of a man with HIV/AIDS over the period 1985 to 1988 was \$52 800; and over the period 1989 to 1993 it was \$96 200. Preventing an HIV infection also avoids the cost to society of the loss of production resulting from premature death. The indirect cost associated with a premature death from AIDS was estimated to be \$253 000.

Table 4.4 shows an estimate of the efficiency of HIV/AIDS education and prevention programs for homosexually active men between 1985 and 1993. Under worst case assumptions, the maximum net direct cost (that is, the cost of education and prevention programs less the savings in direct treatment costs because of infections avoided) was \$185 per year of life saved. If the indirect cost savings are also deducted these programs were estimated to have saved between \$78 million and \$1341 million. This suggests that education and prevention programs were a highly efficient use of resources.

Table 4.4 also shows estimates of the efficiency of HIV/AIDS education and prevention programs for homosexually active men between 1989 and 1993. Expenditure on education and prevention programs for these men during this period was three to four times greater than between 1985 and 1988. The base case (or most likely) estimate of net direct cost per year of life saved was \$25 200. Under the best case assumptions the programs were cost-saving, but under the worst case assumptions their net direct cost was over \$260 000 per year of life saved. When indirect cost savings were added to the benefits, the outcomes ranged from a saving of \$89 million in the best case to a cost of \$49 million in the worst case. A saving of \$3.8 million was the most likely outcome.

These results suggest that expenditure on education and prevention programs for homosexually active men was very efficient in the early years of the epidemic and was most probably efficient during the first Strategy. But the fall in the rate of transmission coupled with the rise in funding for education and prevention programs after 1989 means that the cost of preventing each infection was greater between 1989 and 1993 than between 1985 and 1988.

This analysis should be interpreted cautiously. Because of a lack of time for the analysis and the limitations of the data, the mathematical model is restricted by some simplistic assumptions, especially the assumption that homosexually active men all have the same pattern of risk taking in their sexual behaviour. There is also the possibility that the proportion of change in the rate of transmission attributable to behaviour change may be different from that used here or may have changed with time. The relative contribution of education and prevention programs to behaviour change may also be different to that assumed. Further, there is the question of sustaining behaviour change in the longer term and this is not considered in this model. The decision to adopt safe sexual practices is not made once and for all time. It will be remade many times and in different social contexts. The relative contribution of education and prevention

programs to the maintenance of safe sexual practice may vary over time. The limitations of the foregoing cost-effectiveness analysis emphasise the need for decisions about HIV/AIDS education and prevention policy to be informed by consideration of a range of factors in addition to cost-effectiveness.

**Table 4.4 Efficiency of HIV/AIDS education and prevention programs for homosexually active men, 1985 to 1993**

Items	1985–88 <sup>a</sup>			1989–93 <sup>a</sup>		
	Base case	Best case	Worst case	Base case	Best case	Worst case
Data and assumptions						
Education and prevention expenditures (\$m)	12.6	2.9	17.1	47.2	10.3	56.2
Lifetime treatment cost (\$)	52 800	96 200	52 800	96 200	105 800	77 000
Proportion of behaviour-associated change in transmission rate attributed to education and prevention programs (per cent)	50	100	10	50	100	10
Effectiveness						
Number of cases prevented	1 397	3 850	313	146	277	23
Number of life-years saved	12 573	3 465	2 817	1 314	2 493	207
Cost-effectiveness						
Expenditure per life-year saved (\$)	1 005	82	6 052	35 900	4 100	271 700
Net direct cost (\$m)	-61.1	-367.5	0.5	33.1	-19.1	54.5
Net direct cost per case prevented (\$)	b	b	1 672	230 000	b	2 400 000
Net direct cost per life-year saved (\$)	b	b	185	25 200	b	263 100
Cost benefit						
Indirect cost (\$m)	-353.4	-973.9	-79.2	-36.9	-70.1	-5.8
Net total cost (\$m)	-414.5	-1 341.5	-78.6	-3.8	-89.1	48.7

a. Calculations have been rounded: costs are in 1994–95 Australian dollars. Lifetime treatment costs and life-years saved were discounted at 5 per cent per annum.

b. Net direct cost savings, prevention of cases, and increases in life expectancy.

Source: Hurley, Becker & Butler (1995).

### 4.3.3 Epidemiological and social and behavioural data

Although sex between men has remained the major mode of transmission of HIV in Australia since the beginning of the epidemic, there has been a considerable fall in the number of new diagnoses and the incidence of new infections in this group from the peak of the epidemic in 1984. Data on the actual incidence of infection in this group are incomplete but the estimated annual incidence for 1990 was 400. This level is unacceptably high and the possibility of a second wave of new HIV infection among homosexually active men cannot be discounted (see Section 2.4).

Basic knowledge about the transmission of HIV, particularly in relation to high-risk practices, appears to be widespread and to have increased with time. Information about unprotected male-to-male anal intercourse shows that there has been a remarkable and sustained decrease in the percentage of gay and other homosexually active men engaging in this practice (see Figures 2.6 and 2.7). There has also been a steady increase in the percentage of gay and other homosexually active men who have had an HIV test. There is, however, a degree of uncertainty about the safety of some sexual practices; for example, withdrawal, oral–genital sex, and anal intercourse between positive partners (Crawford et al. 1995).

The patterns of change in both knowledge and practice suggest that safe sex is part of the normal repertoire of male-to-male sex. It is not possible to identify any particular education or prevention measure as the cause of such change. It is reasonable to conclude that the Education and Prevention Program has contributed to the social and cultural change that has taken place.

Educators report that many men find that maintaining safe sexual practices requires continuing support and reinforcement. Strategies to maintain safe behaviour among homosexually active men over a lifetime and the concept of negotiated safety need to be developed and incorporated in education messages. Educational strategies are being designed to focus on the social contexts in which unsafe sex occurs. There will be a continuing need to educate new generations of homosexually active men.

The plateau in infections among homosexually active men is too high and gives rise to the criticism from an economic point of view that programs for this group may be at the limit of their marginal efficiency. It is essential that education and prevention programs are developed to further decrease the practice of unprotected anal intercourse in a cost-effective and appropriate manner. The vigorous debate within the gay community about the effectiveness of current education and prevention programs is a positive sign of that community's continuing willingness to confront this problem. Reassessment is also under way at the national level—through the National Priorities Program the Commonwealth is reviewing gay education planning infrastructure and developing a strategic plan for gay education, including the training of gay educators.

Homosexually active men should remain the highest priority group for the Education and Prevention Program. The process for monitoring how well the priorities identified in the Strategy are implemented should be included in the revised program monitoring and accountability arrangements of a third Strategy.

### **Recommendation 1**

**It is recommended that homosexually active men remain the highest priority for the Education and Prevention Program and that program monitoring and accountability arrangements take account of the need to monitor program implementation in relation to stated priorities.**

**Recommendation 2**

**It is recommended that the Commonwealth, the State and Territory governments and the Australian Federation of AIDS Organisations and AIDS councils reassess and refocus education and prevention measures for homosexually active men, to further decrease the practice of unprotected anal intercourse and thus decrease the rate of HIV.**

**4.4 INJECTING DRUG USERS****4.4.1 Funding**

Projects aimed at injecting drug users account for the highest expenditure in the Education and Prevention Program, with an actual expenditure of 27 per cent in 1993–94 and an estimated expenditure of 25 per cent in 1994–95 (see Table 4.1). The majority of funding is through the MFP and only minimal expenditure through the NPP and NEP.

Most of the expenditure under the MFP has been for needle and syringe exchange programs, which have been implemented in all States and Territories and have gained broad coverage in most areas. At least 10.3 million needles and syringes were distributed in Australia in 1993–94, 42 per cent of them being retailed through pharmacies (Byers 1994). These programs have been accompanied by innovative forms of education to reach a wide range of IDUs; much of this work has been done by IDU groups and AIDS councils. These and other organisations have undertaken extensive work with police, pharmacists, doctors and others to educate them about HIV/AIDS services for IDUs. Implementing services in rural and remote communities, in Aboriginal and Torres Strait Islander communities, in some ethnic groups, and in prisons remains a problem.

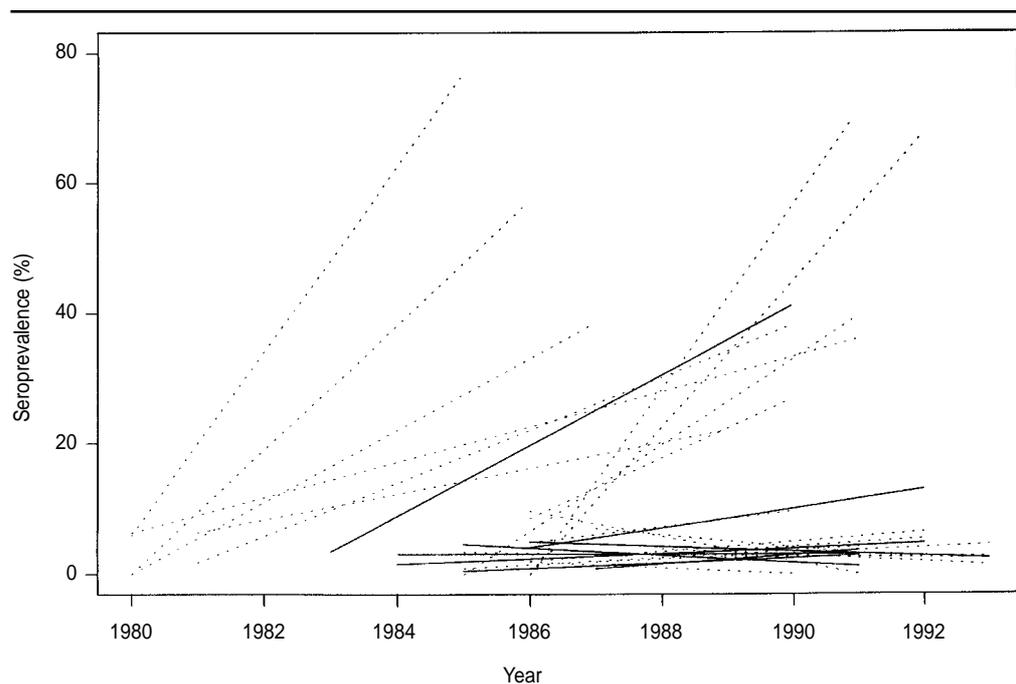
Needle and syringe exchange programs should be complemented by education programs, including peer education and outreach to particular groups of IDUs. Educators and needle and syringe exchange workers consider that IDUs' concern about hepatitis C has substantially increased the demand for needles and syringes.

**4.4.2 The cost-effectiveness of needle and syringe exchange programs**

The estimates of the cost-effectiveness of needle and syringe exchange programs presented in this section are based on an international comparison of the seroprevalence of HIV among IDUs in a number of cities in a number of countries. This information is the outcome of a research project first funded by the Commonwealth AIDS Research Grants Program and completed on commission from the evaluation (Hurley, Jolley & Kaldor 1995). The approach is very different from and more reliable than that used to estimate the effectiveness of education and prevention programs for homosexually active men—a fact determined by differences in the type of data available.

The change in the seroprevalence of HIV among IDUs, comparing cities around the world that have introduced needle and syringe exchange programs with those that have not, was analysed to determine the program's effectiveness (see Figure 4.3). At the beginning of the period of observation the average seroprevalence of HIV was approximately 3 per cent in all locations in the study. At the end of the observation period the average seroprevalence in locations where a needle and syringe exchange program had been introduced was 6 per cent, compared with an average seroprevalence of 21 per cent in locations where a needle and syringe exchange program had not been introduced. This suggests that needle and syringe exchange programs are effective at reducing HIV incidence rates. A major limitation of the analysis is that the seroprevalence surveys used in the different locations varied widely in scope, method and the characteristics of the IDUs included, and they were not conducted according to any consistent plan.

**Figure 4.3 Pooled HIV seroprevalences for locations with a first measurement less than 10 per cent and a subsequent measurement four or more years later**



Note: The first and most recent pooled seroprevalences are plotted, joined by an unbroken line for locations that had a needle and syringe exchange program introduced when seroprevalence was below 10 per cent and by a broken line for locations that did not have a program introduced over the period.

Source: Hurley, Jolley & Kaldor (1995).

These findings are supported by the conclusions of a comprehensive international review of needle and syringe exchange programs prepared for the United States Centers for Disease Control and Prevention (Lurie & Reingold 1993).

Estimates of the cost-effectiveness of needle and syringe exchange programs in

## NEEDLE EXCHANGE—A COOPERATIVE EFFORT

If HIV/AIDS had been around in the 1970s Damon Brogan believes he would have contracted the virus, along with most of his friends.

'We were all heavily into injecting drugs and we had no information in those days about safe needle use,' he said. 'We knew we could catch hepatitis B, but we didn't know how dangerous the virus was and we could not get a hold of clean equipment anyway, so my whole generation, including me, got hepatitis. I had hep B for about 16 years and also contracted hep C and hep D but later in the '80s when I had a scare with HIV, when I thought perhaps I had picked it up, I realised that if HIV had been around earlier, we all would have got it.'

Damon said after his HIV scare he realised how lucky he had been and so he became actively involved in consumer advocacy for things like needle exchange programs and safer injecting drug use. Today he is coordinator of SAVIVE—South Australian Voice for Intravenous Education— attached to the AIDS Council of South Australia.

SAVIVE is recognised as one of the most successful peer education programs in Australia aimed at decreasing the transmission of HIV/AIDS amongst injecting drug users. 'We do this primarily through peer education and peer-operated needle exchange,' he explained. 'The users either come here to the AIDS Council and get their needles or we have a system of community networks. In Adelaide the drug scene is fairly tribal—you don't go to a suburb and score on the street, you do it in people's home—it is very suburban, you get in by introduction only. So over the years we have recruited people with standing within their tribes to carry out needle exchange and peer education for us. We call them networkers.' Damon said there are more than a 100 people like that to whom he sub-contracts the SAVIVE needle exchange. 'These people act as role models and we believe there has been a substantial behaviour change, so that safer drug use behaviour is the norm now among most regular injectors in Adelaide.'

Damon said he had seen substantial behavioural change since 1989 and it is being sustained. 'We work closely with the Drug and Alcohol Services Council because in South Australia drug and alcohol services now coordinates HIV/AIDS services for injecting drug users on behalf of the Health Commission. They also operate a lot of needle exchanges across the State and they have recruited a lot of suburban pharmacies for this purpose,' he said. 'We cooperate very closely with the gay community and the AIDS Council and, together with the Drug and Alcohol Council, we have found this very beneficial to the work we are undertaking.'

Damon said that in South Australia the rate of infections attributed to injecting drug use in recent years was very low. 'Officially there have been no new cases among injecting drug users as the principle risk factor in the last couple of years but it is the threat of what could happen that always concerns me, so we must continue to be vigilant in our safe injecting drug use programs,' he warned.

Australia in 1991 were developed using base case (the most plausible), best case and worst case assumptions (see Table 4.5). An estimated 3000 cases of HIV were avoided in Australia in 1991 through the operation of needle and syringe exchange programs. Using gross expenditure (without deducting any direct or indirect cost savings), the cost per life-year saved varied from \$50 in the best case to \$7000 in the worst case. The most likely cost per life-year saved was \$350. The savings in treatment costs due to prevention of HIV infection more than offset the operating costs of the programs. This means that the programs were cost-saving, even under the worst case assumptions. As well, the analysis presented here underestimates the likely cost-effectiveness of needle and syringe exchange programs because they may also lead to a decrease in the transmission of hepatitis B and C. If these additional benefits were measured, both the number of years of life saved and the net direct cost savings would be increased.

**Table 4.5 Cost-effectiveness of needle and syringe exchange programs: Australia, 1991**

Items	Base case	Best case	Worst case
Data and assumptions <sup>a</sup>			
Cost per needle distributed (\$)	1.40	0.70	2.80
Number of IDUs per 1000 population	5	10	3
Annual reduction in rate of increase of seroprevalence attributed to programs (%)	3.4	6.1	0.6
Effectiveness			
Number of cases prevented	2 900	10 300	300
Number of life-years saved	24 100	86 300	2 500
Cost-effectiveness			
Expenditure per life-year saved (\$)	350	50	7 000
Net direct cost (\$m)	-266.7	-984.3	-11.5
Net direct cost per case prevented	b	b	b
Net direct cost per life-year saved	b	b	b

a. Additional assumptions for all analyses:

- Number of needles distributed in Australia in 1991 was 6.3 million.
- Lifetime treatment cost is \$96 200.
- Average age of infection of IDU is 24 years.
- Life expectancy of 24-year-old IDU is 40 years (discounted 17.2 years).
- Average time from HIV infection to death is 12 years (discounted 8.8 years).

b. Net direct cost savings, prevention of cases, and increases in life expectancy.

Note: Calculations are rounded; costs are in 1994–95 Australian dollars; lifetime treatment costs and life-years saved are discounted at 5% per annum.

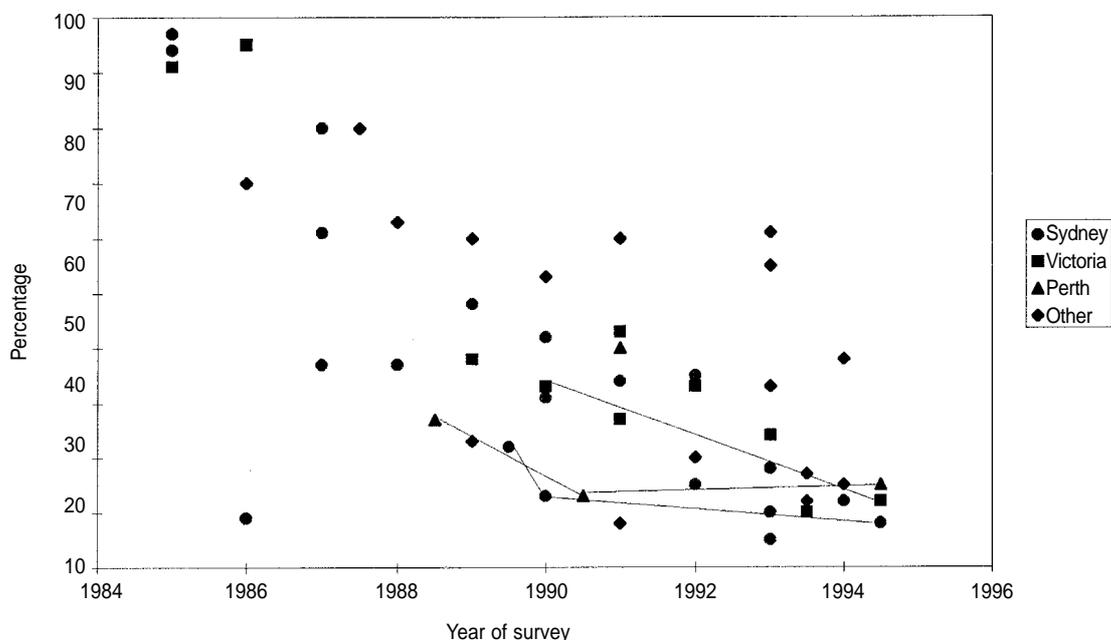
Source: Hurley, Jolley & Kaldor (1995).

#### 4.4.3 Epidemiological and social and behavioural data

With the exception of the sub-group of men who report homosexual contact, the prevalence of HIV infection among IDUs in Australia is less than 5 per cent. This figure is low when compared with prevalence rates in a number of

developed countries. The estimated incidence of HIV in heterosexual IDUs peaked in 1987, with 80 infections for that year. The estimate for 1993 was 20 cases (see Section 2.5). Social and behavioural data relating to IDUs show that the self-reported rate of sharing needles and syringes has remained consistently below 50 per cent since 1989 (see Figure 4.4). Large national surveys show a decline in sharing to below 20 per cent in 1994. The majority of IDUs clean injecting equipment before it is reused, although a large minority still do not do so on every occasion of injecting (Crofts et al. 1995).

**Figure 4.4 Proportion of injecting drug users sharing needles and syringes in the last month, multiple survey sites, 1984–94**



Source: Crofts et al. (1995).

Injecting drug users remain a priority for the Education and Prevention Program because of the potential for rapid spread of infection in this group. It is highly probable that needle and syringe exchange programs and other National HIV/AIDS Strategy programs directed at IDUs—such as peer education and community development—are responsible for the low prevalence of HIV seen in this group in Australia. The programs are also highly cost effective.

It should be recognised that the programs also provide a broad public health response to a number of blood-borne pathogens. It is appropriate that this response is funded from the National HIV/AIDS Strategy since these pathogens share the same mode of transmission as HIV.

**Recommendation 3**

**It is recommended that injecting drug users remain a priority for the Education and Prevention Program. Community development and peer education for injecting drug users should be strengthened.**

## 4.5 ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

### 4.5.1 Funding

Education and prevention activities for Aboriginal and Torres Strait Islander communities have been funded under all four funding programs and accounted for 8 per cent of Education and Prevention Program expenditure in 1993–94 and 11 per cent of estimated Program expenditure in 1994–95 (see Table 4.1). Only a small proportion of NEP funds was spent on Aboriginal and Torres Strait Islander initiatives. Twenty eight per cent of NPP expenditure in 1994–95 was on education and prevention for Aboriginal and Torres Strait Islander people.

The States and Territories spent \$2.2 million on education and prevention activities for Aboriginal and Torres Strait Islander communities in 1993–94 under the MFP and the SFP (Table 4.6). The Northern Territory spent 45 per cent of its total MFP monies on Aboriginal and Torres Strait Islander projects.

**Table 4.6 Education and prevention programs for Aboriginal and Torres Strait Islander people: Matched Funding and Special Funding Program expenditure, by State and Territory, 1993–94**  
(\$'000)

State/Territory	Matched Funding Program	Special Funding Program	Total Funding
NSW	446	454	900
Vic	160	88	248
Qld	201	-	201
WA	90	108	198
SA	87	167	254
Tas	5	-	5
NT	304	55	359
ACT	-	16	16
Total	1 293	888	2 181

Notes: The project register was analysed for percentage of funding on the Target Group of Aboriginal and Torres Strait Islander people. In the project register the term Target Group refers to each of the client groups that have been identified as beneficiaries of the outcomes flowing from the project. This table provides an analysis of Expenditure Category by Target Group. This is achieved by first apportioning project costs to the Expenditure Categories identified by each project and then apportioning the costs relating to education and prevention to the Target Groups identified as beneficiaries of each project. As a result, funding for this group is higher than that seen in Table 4.1 (MFP expenditure is \$1 million), which shows funding for Aboriginal and Torres Strait Islander people as a primary target group by expenditure category only. SFP excludes training for health care workers, research, evaluation and administration. SFP figures were not available for Queensland, although the State received SFP funds.

Source: Commonwealth of Australia (1995).

All other jurisdictions spent less than 8 per cent of their MFP allocation. Because of administrative difficulties, SFP funds were not fully spent in 1993–94.

Localised approaches were evident in the Aboriginal and Torres Strait Islander education and prevention projects, reflecting the diversity of Aboriginal and Torres Strait Islander communities. Resources designed for use in specific geographical areas or with specific cultural groups—such as videos, posters, paintings, radio programs and pamphlets—have been produced. Among the agencies involved in these projects were Aboriginal medical services, State and Territory regional health services, and Aboriginal cooperatives.

#### **4.5.2 Epidemiological and social and behavioural data**

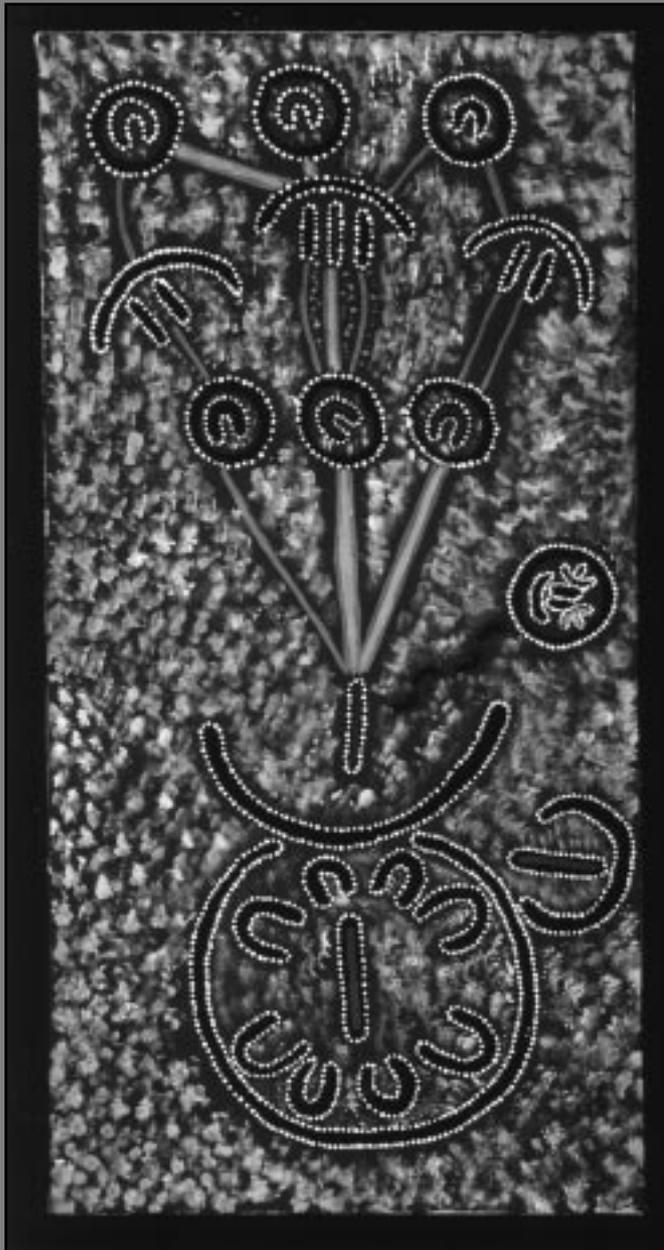
Although the available surveillance data show that the rate of HIV infection among Aboriginal and Torres Strait Islander people is similar to that among non-indigenous Australians, it would appear that the former rate is increasing. This is in contrast to the trend in the general population. An increasing proportion of Aboriginal and Torres Strait Islander case reports suggest heterosexual contact as the probable mode of transmission, even though sex between men remains the predominant mode. Surveillance data indicate very high rates of STDs in the Aboriginal and Torres Strait Islander population. Rates of STDs are a marker of sexual risk and the infections are known to facilitate HIV transmission (see Section 2.6). The extent of injecting drug use among Aboriginal and Torres Strait Islander people is unknown, but educators and needle and syringe exchange workers report that it is common in some urban and rural communities. These data all support the conclusion that a major outbreak of HIV infection among Aboriginal and Torres Strait Islander communities is probable.

A number of factors limiting the effectiveness of the Education and Prevention Program for indigenous people were identified: inadequate health infrastructure; competing primary health needs; a lack of intersectoral coordination; inadequate training and support for indigenous health workers; a reluctance on the part of Aboriginal and Torres Strait Islander communities to see HIV/AIDS as a priority; and a reluctance by communities to confront particular practices such as homosexuality or injecting drug use.

Several recent initiatives will redress some of these problems. ANCA held an Aboriginal and Torres Strait Islander Forum on Sexual Health in May 1995 and the Office for Aboriginal and Torres Strait Islander Health Services is reviewing mechanisms to improve the training of indigenous health workers. Further, the establishment of the ANCA Aboriginal and Torres Strait Islander Working Party on Sexual Health will help to resolve the strategic difficulties. The transfer of responsibility for Aboriginal and Torres Strait Islander health to the Department of Human Services and Health should resolve some of the health infrastructure problems.

### Pikatjarra story

This painting tells the story of how people pass STDs or HIV (pika) to one another. Maybe one man goes to town and gets drunk then starts chasing around for kungka. They might camp with them for one night, next morning they might go with another one, That way, kungkas' might go round with big mob wati. That woman, she might have that pika inside. He might come home and give that pika for other kungka. Kungka might give it for man, man might give it for kungka, and that's how it gets passed around.



### Doctor Wangka

I'm thinking that when a person gets HIV (pika) that doctors might think that they are boss for that pika. 'I gotta look after 'em. I got needles and things,' that doctor might think. What about health worker? Talk to health worker to find out what family are thinking. If that wati gets pika and goes to see the doctor that doctor might take blood. When that doctor tells that person he has HIV, he can't go and sit down separate way from family. That Doctor should see Aboriginal health worker, or brother or sister or cousins only if that Wati is too shame to tell them himself. If family wants that person to stay with family, health workers got to tell. It's important for doctors or nurses to understand the right way for talking about pika business with Yanangu.

by Djala Kurkura  
Andrews, health worker  
at Areyonga, a remote  
Aboriginal community in  
the Northern Territory.

Reprinted with the kind permission of the indigenous artists, Iris Taylor, Janet Carroll, Nellie Brumby, Margaret Sitzler, Irene Carroll, Louise Whisky and Djala Andrews.

## THE DESERT STORY

When Kerry Arabena, a social worker of Torres Strait Islander decent, took her small child to Alice Springs in search of a new life, she never expected to spend three and a half years in a remote community coordinating Australia's most remote independent medical centre, the Pintubi Homelands Health Service.

'I had been working with Family Services in Alice Springs for a year when I went on my first bush trip. Three months later, I moved to the very place, lock, stock and barrel! I never did go on any other bush trips with the welfare mob, I was sold on this place!' Kerry said enthusiastically.

Kerry now runs the Tri-state Program, a cooperative effort involving a committee of health professionals representing four State governments and observed by members of Aboriginal organisations, primary health care agencies and the National Centre in HIV Epidemiology and Clinical Research. 'Having this expertise available as a reference group will go a long way to ensuring the success of the program,' she said.

Kerry recalls the excitement of getting the job and the realisation that she was part of a team that was making a concerted effort to rid the region of STDs. 'I am a firm believer that the program can make a change. For some people, the best STD treatment may be available in an adjoining State. We acknowledge the high mobility of people in the region and aim to provide patient treatment and follow-up services where they are needed, regardless of the State Borders. This strategy is fully backed by the respective governments and is a breakaway from the traditional responses to disease control in this part of the country.'

Travelling is a norm in this job. Kerry sometimes travels as much as 1500 kilometres a week to hold workshops in the desert. 'I have never travelled so much in my life!' But travelling to a remote-area place and to a major capital city offers some sharp contrasts. 'It is important to know the "proper protocol" whatever the venue,' she said.

Kerry admits work in the bush has its difficult moments, although she said it has been mostly enjoyable. 'Talking about sexual health has to be done in a way that includes whole-life issues,' she said. 'It is a holistic approach to health, and we use the cultural expertise available through the elders, especially the women, to talk to the younger people about how communities kept themselves healthy in the past and the importance of prevention in the control of disease.'

'We hold "Risky Business" workshops in places so that people can think about situations in which they will be more at risk of contracting STDs and HIV and put in place some strategies so that Aboriginal people will be more able to control the agenda in the future.'

'People want to establish how HIV will effect their communities, so that they are prepared. The Tri-state Program plays a vital role in helping them do this,' she said.

The failure of current programs to make an impact on the high levels of STDs and the recent evidence of increasing rates of HIV infection in indigenous communities support the urgent need for continuing education and prevention efforts. These should be placed within the context of sexual health and injecting drug use. Strategies based on best practice models that acknowledge the diversity of indigenous communities are required.

These efforts must be supported by surveillance data and a knowledge of social and behavioural factors relating to the transmission of HIV. This information has been available to only a limited extent. The relevance of the data has not been apparent to individual communities and this perception is supported by the poor track record of researchers who, in the past, have not worked in partnership with Aboriginal and Torres Strait Islander people. Consultations showed an increasing willingness by indigenous people to have epidemiological and social and behavioural data collected, provided a partnership approach is taken.

#### **Recommendation 4**

**It is recommended that the Commonwealth, the Intergovernmental Committee on AIDS and the Australian National Council on AIDS continue to support intensive education and prevention activities among Aboriginal and Torres Strait Islander communities. These activities should be placed within the broader sexual health and injecting drug use contexts and use models of best practice.**

## **4.6 PEOPLE LIVING WITH HIV/AIDS**

Projects specifically for people living with HIV/AIDS have been funded under the NEP, the NPP and the MFP; they accounted for 9 per cent of expenditure in 1993–94 and an estimated expenditure of 6 per cent in 1994–95 (see Table 4.1). People living with HIV/AIDS also make use of projects tailored to other groups, such as those for homosexually active men, and projects funded under the Treatment and Care Program that provide some education and prevention.

A major initiative has been the Health Monitoring and Maintenance education program funded by the NEP, which has involved projects at AFAO, the Australasian Society for HIV Medicine and the Royal Australian College of General Practitioners.

The highest expenditure for people living with HIV/AIDS occurs through the MFP. The States and Territories use a range of education strategies—among them counselling services and support groups at AIDS councils, treatment information services, positive living centres and education media. People with medically acquired HIV/AIDS (for example, people with haemophilia and transfusion-related infection) are a sub-group of people living with HIV/AIDS. Members of this sub-group were all affected at one time and are often also

affected by other blood-borne pathogens, particularly hepatitis C. This group makes use of tailored projects funded under the MFP and the NEP.

Approximately 14 500 people have been diagnosed with HIV infection in Australia and over 4000 of these people have died. It is estimated that the number of people living with HIV/AIDS will continue at this level for at least the next 10 years (see Section 2.1). It is essential therefore that they play an integral part in prevention strategies and that they have access to information to enable them to maximise their quality of life. There is limited social and behavioural data available on people living with HIV/AIDS. A study of HIV-positive men in Sydney has, however, shown that this group was well informed about HIV and AIDS and has made a wide range of changes to their lifestyle and behaviour in order to improve their health (Prestage et al. 1995a).

The NAPWA submission emphasised the importance of peer support, the central role of people living with HIV/AIDS in planning and service delivery, and the need for both education and support services. It is important that people living with HIV/AIDS are partners in, not just clients of, services delivering programs. The Gay Education Strategies Project is examining how existing education programs could include programs for people with HIV/AIDS and how prevention initiatives can successfully include them.

The education needs of people living with HIV/AIDS should be incorporated in prevention strategies. The Commonwealth cannot be prescriptive about the roles organisations take at the local level in providing services to people living with HIV/AIDS but it, the States and Territories and non-government organisations should support the very important role of people living with HIV/AIDS in education and prevention.

#### **Recommendation 5**

**It is recommended that the Commonwealth, the States and Territories, and non-government organisations support the very important role of people living with HIV/AIDS in education and prevention strategies.**

## **4.7 PRISONERS**

The MFP and the SFP have funded projects for prisoners (see Table 4.1). In some jurisdictions corrective services departments have also allocated from their own budgets funding for HIV education and prevention. This is consistent with making education and prevention a mainstream function. In all jurisdictions some education is offered at the time of entry to prison and there is an increasing trend towards education by peers.

Nevertheless, education and prevention strategies for prisoners have been implemented in only a limited way. As in most countries of the world, injecting equipment is not available in prisons and bleach is available to only a limited extent. A methadone maintenance program operates in New South

Wales prisons, but there is no, or very limited, access to methadone programs in other prison systems. Apart from the remand centre in the Australian Capital Territory, condoms are not available in any prison system (Robinson 1994). The National HIV/AIDS Strategy identified programs for Aboriginal and Torres Strait Islander prisoners as a priority for the SFP, but there have been only limited initiatives for this group.

The prevalence of diagnosed HIV infection upon reception in Australian prisons has remained at less than 0.5 per cent between 1991 and 1994 (see Section 2.5). This rate is at least eight times the estimated prevalence of diagnosed HIV infection in the Australian population as a whole. Data on the incidence of HIV in prisons are not available, although there has been one published report of a case of transmission of HIV in prison (Dolan et al. 1994). Concern about HIV in prisons is particularly relevant to the Aboriginal and Torres Strait Islander community since this group is over-represented in the prison population.

Social and behavioural data provide evidence that considerable risk behaviour occurs in prisons and that the extent of this behaviour is not declining. Almost half of all prisoners have a history of injecting drug use and about half of inmates with such a history report injecting in prison. Most of these prisoners reported sharing injecting equipment in prison. Bleach has been increasingly used to clean injection equipment since the late 1980s, but there is now doubt about its efficacy. Approximately 10 per cent of male prisoners report engaging in anal sex while in prison. Condoms are rarely used in prison (Crofts et al. 1995).

Although data on the transmission of HIV in prison are not available, the prevalence rate of HIV upon reception in prison and the social and behavioural data suggest that current education strategies need to be supplemented by prevention strategies that have been shown to be effective in the general community. As minimum interventions, prisoners should receive peer education and have ready access to bleach, condoms and methadone programs.

#### **Recommendation 6**

**It is recommended that individual States and Territories and the Intergovernmental Committee on AIDS work with the departments responsible for corrective services to ensure that in prisons there is continued emphasis on the implementation of education and prevention strategies that have been shown to be effective in the general community.**

## **4.8 SEX WORKERS**

Projects aimed at sex workers accounted for 9 per cent of total Education and Prevention expenditure in 1993–94 and 8 per cent of estimated expenditure in 1994–95 (see Table 4.1). With the exception of a small expenditure under the

NPP in 1993–94, all the projects have been carried out under the MFP. The aim of the NPP project was to develop for sex workers a resource providing information about HIV and STDs, which is consistent with the move towards the broader sexual health context.

Community-based sex worker organisations were funded in all States and Territories, although the projects were limited in scale in the Northern Territory and Tasmania. The projects provided peer education in the sex workers' workplace and for other people who work in the sex industry; it also produced educational resources. Sex worker organisations have contact with workers in all parts of the industry (for example, brothels and private, street and escort workers). Other activities include provision of free condoms and liaison with police and health services. There were projects directed at female, male, trans-gender and international sex workers. Some sexual health services provide medical care and counselling for sex workers.

Data on the prevalence of HIV in sex workers are limited but they suggest that for female workers prevalence is low. This is supported by information showing low rates of STDs in this group. The possible exceptions to this are female sex workers from countries in South-East Asia and sex workers who inject drugs (see Section 2.8).

Large-scale change has occurred among some sex workers in the last decade—in some segments of the industry (for example, in legal brothels) condom use with clients now approaches 100 per cent. The data on workers in different parts of the sex industry—for example, street workers, and illegal sex workers—are limited (Smith et al. 1995). Educators report that many such workers are more vulnerable to pressure to engage in unsafe sex. A number of submissions to the evaluation said that sex workers' use of condoms with clients is heavily influenced by prostitution laws: these differ between jurisdictions and sex workers' work is a criminal activity in many jurisdictions (see Chapter 8). Interpretation of data from social and behavioural research is problematic largely because of the varied legal frameworks.

There is a continuing need to provide education aimed specifically at sex workers because of the high risk associated with their work. And programs must have ways of reaching those who work in all parts of the industry. Because of the high levels of transmission of HIV in Asia, projects focussing on illegal Asian and other international workers are particularly important. Current funding should be maintained.

### **Recommendation 7**

**It is recommended that the Commonwealth and the States and Territories maintain current funding for education and prevention activities directed at sex workers and their clients.**

## THE BROTHEL BUSINESS

When the HIV/AIDS epidemic hit Australia in the mid-1980s and prostitution was put under the microscope by law makers, the commercial sex work industry went into decline and it has never really recovered, according to Loretta, who runs the exclusive brothel, Spoilers, in inner-city Melbourne.

Spoilers is a legally operating establishment under Victorian law, registered with the Health Department, respected by the local police, and accredited by the Prostitutes Collective of Victoria as a place that abides by a 10-point checklist of health and industrial safeguards.

‘But while it is good for the girls and the health of the community, it’s tough on business,’ Loretta admits. ‘Believe it or not but, while some men were turned right off visiting a prostitute because of the threat of AIDS, others stopped coming just because the brothels were made legal,’ she said. ‘The sense of doing something illicit was the turn-on for many people.

‘It’s the same with condoms. In the old days some girls would charge a client extra if they wanted to use a condom. Now, in the age of AIDS, where most working girls would not think of having sex without a condom, clients offer more money to do it without one.’

Loretta said she has seen many changes in the industry over the years and it never ceases to amaze her.

‘We started off engaged in a totally illegal practice and although we were regularly raided by police and were fined, we carried out our work with a minimum of fuss to the community,’ Loretta explained. ‘Then the Cain Labor Government brought in legal brothels based on purely planning grounds, which saw a lot of girls move off the streets and into regulated premises.

‘Now the Kennett Liberal Government is trying to close us down altogether with draconian new laws that permit police to enter our places at any time without a warrant and to enforce fortnightly health checks on the girls, which is unrealistic and unnecessary,’ she said.

Loretta is adamant that no-one can point the finger at commercial sex workers as a cause for the spread of HIV/AIDS in Australia. ‘The majority of prostitutes, either working alone or in brothels, responded responsibly to the threat of AIDS and enforced the use of condoms by clients.’

But she admits that drug use by prostitutes is a continuing threat. ‘Many of the working girls use drugs and when they are desperate for a hit they would do anything—even unsafe sex— to make some extra money and this is a real health risk.’

Loretta doesn’t knowingly allow girls who take drugs to work in her establishment. ‘They are trouble to themselves and to the reputation of the industry,’ she said. ‘The problem is many of the brothels that are run by men are not as strict as I am and so perhaps it is only that heterosexual sex is such a difficult way to transmit HIV that there has not been more of it.’

## 4.9 TRAINING FOR HEALTH CARE WORKERS

The NEP, the NPP and the MFP have funded training for health care workers; it accounted for 6 per cent of the total Education and Prevention expenditure in 1993–94 and the same proportion in 1994–95 (see Table 4.1). In addition to expenditure reported in Table 4.1, a further \$4.7 million was spent under the MFP and the SFP in 1993–94 on training generally (including health care workers as well as volunteers, emergency service workers, educators and staff).

The NPP funded a number of projects for health care workers, among them projects in association with professional medical bodies and projects for indigenous health educators. The projects involved health maintenance and monitoring, travel information, discrimination and dentistry, and they ranged from basic information to specialised training.

The highest expenditure for health care worker training was under the MFP: all States and the Northern Territory funded projects. New South Wales is the only jurisdiction to substantially fund HIV/AIDS study grants, which were incorporated in the MFP in 1993–94. This incorporation in the MFP limits the extent to which health care professionals in States and Territories with smaller epidemics can gain access to specialised training, although all jurisdictions can make study grants under the MFP as appropriate.

Education about HIV/AIDS is part of the pre-service training of health care workers; post-training education is undertaken by professional bodies. Both are examples of the mainstreaming of education and prevention for health care workers.

Training initiatives for health care workers appear to have been well implemented. The exception to this is training for indigenous health care workers, a matter raised repeatedly during the consultations and at the Aboriginal and Torres Strait Islander Forum on Sexual Health. Consultations and submissions also stressed that training for workers in education and prevention, as well as treatment and care, is required—examples are indigenous health care workers and peer educators of homosexually active men.

Training for health care and education workers is fundamental to the effectiveness of all the Strategy's programs. The trend for these activities to be adopted by mainstream education services and professional bodies should continue with two exceptions: training for peer educators of homosexually active men and training for indigenous health care workers.

### **Recommendation 8**

**It is recommended that the Commonwealth and the States and Territories continue to fund training for health care workers (including indigenous health care workers) and peer educators. The trend for education of health care workers to be mainstreamed should continue.**

## 4.10 GENERAL COMMUNITY

General community education accounted for 7 per cent of total Education and Prevention Program expenditure in 1993–94 and 10 per cent of estimated expenditure in 1994–95 (see Table 4.1). These figures are somewhat misleading since funding for a number of other sub-groups of the general community is reported separately—young heterosexuals, women, travellers, and people from non-English-speaking backgrounds, for example. The majority of funding for all these general community groups is through the NEP and the MFP; it accounted for a further 8 per cent of total expenditure in 1993–94.

The mainstream media have played a very important part in community education. Their work has been facilitated by the media liaison officer in the AIDS/Communicable Diseases Branch of the Department of Human Services and Health, by the many members of the partnership who have developed good relationships with the media, and by journalists who provide consistent, high-quality, factual information.

The data from social and behavioural research show that between 1986 and 1995 there has been an increase in the reported rates of change in sexual behaviour in response to the HIV/AIDS epidemic. Table 4.7 shows that there has been an increase in the proportion of males always using condoms between 1986 and 1995, in all age groups. There has also been a doubling to trebling in the reported rate of always using condoms among single sexually active men and women (Smith et al. 1995). Figures on retail sales of condoms from a market leader show an increase from 18.4 million sales in 1985–96 to 41.3 million sales in 1994–95 (Ansell 1995, pers. comm.).

The number of diagnosed cases of HIV infection and AIDS in Australia associated with heterosexual contact has been relatively small (see Section 2.1). And although there has been a steady increase in the number of new HIV diagnoses in women who have become infected through heterosexual contact this number remains low (see Section 2.9). It is reasonable to conclude that the

**Table 4.7 Percentage of male non-virgin respondents using condoms, Australia, 1986 and 1995**

Age (years)	1986		1995	
	Always	Number	Always	Number
16–24	9.5	126	29.1	141
25–34	6	183	23.4	188
35–44	2.9	175	12.5	192
45+ <sup>a</sup>	4.2	167	13.2	167

a. 45–54 years in 1995, 45–59 years in 1986.

Note: In 1986 males were asked how often they used condoms; in 1995 the 'Always' category was constructed from those who said that condoms (lubricated and unlubricated) were their main method of contraception or that they always used condoms in addition to other forms of contraception with regular partners and always used condoms for protection with casual partners.

Source: Smith et al. (1995).

Education and Prevention Program has contributed to the change in attitudes and behaviours and the low rates of infection in the heterosexual community.

Although community education is necessary to provide information about transmission and to promote a broad climate of understanding about HIV/AIDS, the current funding levels are open to question in the face of more pressing priorities. The monitoring of both epidemiological and social and behavioural trends must continue and the result must be used to inform funding levels in the future. The level of funding for education should be decreased in a third National HIV/AIDS Strategy and freed resources should be directed to priority groups.

#### **Recommendation 9**

**It is recommended that the Commonwealth and the States and Territories continue to provide education to the general community but that the funding level be decreased.**

### **4.11 YOUTH**

Specific projects for youth have been funded under the NEP, the NPP, the MFP and the SFP (see Table 4.1). Disadvantaged youth and school-based youth have been the focus of a number of projects in most States and Territories. Numerous projects in the States and Territories were also directed at young people, in particular Aboriginal and Torres Strait Islander projects, AIDS council projects, injecting drug use education projects, and projects in rural and remote areas.

Social and behavioural and epidemiological data do not allow us to draw firm conclusions about the effectiveness of the programs for youth but the available information is encouraging. The epidemiological information shows that the median ages at HIV and AIDS diagnosis have been in the low and high 30s respectively (see Section 2.1).

The data from social and behavioural research are not sufficient to determine the extent of change in condom use among Australian youth, although they suggest that condom use has increased. The rates of condom use among school students appear reasonably high, while the rates among homeless and refugee-based youth appear much lower (Smith et al. 1995).

Surveys among university students in Sydney and Melbourne found that the percentage of 18- and 19-year-old students reporting that they always use condoms for vaginal sex with casual partners has increased between 1990 and 1994 (see Figure 4.5). Condom use for vaginal sex with regular partners also increased. Students displayed high levels of knowledge about HIV/AIDS (Smith et al. 1995).

## REACHING MEN IN THE SUBURBS

When the HIV/AIDS Program of the Queensland Health Department restructured in 1991 the HIV/AIDS and Sexual Health Section decided to mount a coordinated campaign to reach those hundreds of men who have sex with men out in the regions and suburbs and who had never been successfully reached with the HIV/AIDS message before.

‘These men—some of them gay, others non-gay-identifying, and some who have sex with both men and with women—are found all over Australia and because they do not have contact with an identified gay grouping they miss out completely on support networks and are vulnerable to contracting and transmitting HIV,’ Larry Pierce, the Health Department’s HIV/AIDS Program Adviser, explained.

‘While the gay community in all Australian cities has mobilised in the fight against the spread of HIV, these isolated people, particularly those non-gay-identifying men who have sex with men, are the biggest threat to the containment of the virus.’

Larry said it was clear that the Department needed to work cooperatively with other parties to have a chance of reaching these people and so formal liaison was set up between the Department, the Queensland AIDS Council (QuAC) and regional health authorities. The Regional Response Action Plan—RRAP—was launched and a strategy developed by QuAC.

‘Already we had in place a regional HIV/AIDS network incorporating mainstream service providers and regional health authorities and, combined with QuAC, we set about identifying key people in communities, usually gay men, who began developing support projects in their own areas. This process was developed by an AIDS Council outreach worker.

‘They would run low-key advertisements in local newspapers calling for interested people to ring a local 008 phone number that was resourced and supported by the local outreach RRAP officer. The AIDS Council trained our regional health workers about men who had sex with men and in return the regional office would provide phone, fax, office and travel support.

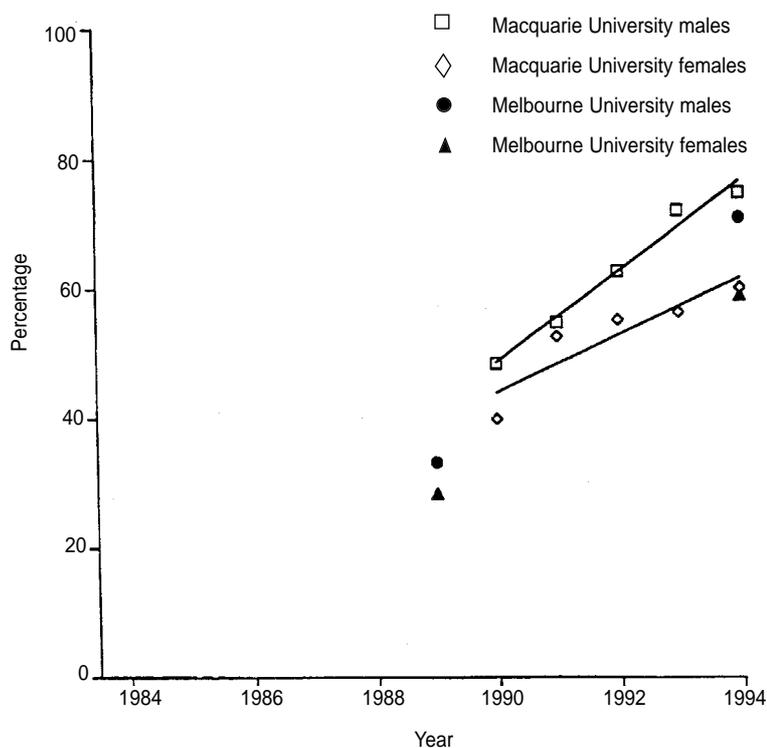
‘Together they would undertake community development and peer education around local beats, recruiting gay men as volunteers to continue the work. We would resource them with condoms, educational materials and the Regional Health Authority would work to influence and gain support from local police, civic leaders, opinion makers, ministers of religion, and the like.

‘Soon you would get a self-sustaining thing going, where the AIDS Council could continue to support the network and eventually the Government could pull out altogether.

‘RRAP has been a model of cooperation and partnership between the Government, affected community organisations, and local people in tackling HIV/AIDS at a grass-roots level.

‘The results have been extremely encouraging and the effort very worthwhile,’ Larry said.

**Figure 4.5 Percentage of 18- and 19-year-olds reporting that they always use condoms for vaginal sex with casual partners: selected universities, by sex, 1984 to 1994**



Source: Smith et al. (1995).

The second Strategy stated that HIV/AIDS education in schools has the potential to be the most comprehensive and efficient means of long-term access to the general community. A survey of school-based HIV/AIDS education carried out in all States and Territories (with the exception of Tasmanian government schools) showed that the number of students participating in HIV/AIDS education increased between 1992 and 1995. The increase was seen in every grade from 5 to 12 (see Table 4.8).

Programs for youth appear to be working. The data, however, are insufficient to allow conclusions about marginalised groups. These groups will be reached through specific programs for high-priority groups and this is appropriate. School-based education should continue to be the major strategy for education for youth in the general community. There is a need for improved data on marginalised youth to ensure that their needs are been met by current programs.

#### **Recommendation 10**

**It is recommended that school-based education, in a broader sexual health context, remain a primary approach to education for youth and that it be adequately funded.**

**Table 4.8 Number of school students receiving HIV/AIDS education: Australia, 1992 and 1994**

Grade	Number		% of total students	
	1992	1994	1992	1994
Grade 5	13 779	31 680	11	24
Grade 6	34 705	50 256	18	37
Grade 7	67 251	73 149	38	56
Grade 8	75 694	74 754	42	58
Grade 9	105 221	89 363	57	71
Grade 10	121 028	93 645	66	77
Grade 11	65 162	51 837	39	50
Grade 12	50 535	37 644	34	41
Total of grades	533 375	502 328	39	52
Total of students surveyed	1 353 791	975 262		

Note: The 1992 survey covered all schools in the Australian school system; the response rate was 75 per cent. The 1994 survey covered all schools in Australian school system, except Tasmanian government schools; the response rate was 55 per cent.  
Source: HIV/AIDS Schools Network of Australia (1995).

## 4.12 OTHER ASPECTS OF THE EDUCATION AND PREVENTION PROGRAM

### 4.12.1 Mainstreaming

The Education and Prevention Program has been delivered through a mixture of specialised and general services. This is called mainstreaming and its extent has varied with geographic location, priority group and education strategy. The lack of definition of the broader sexual health context and the absence of a national sexual health strategic plan, the subsequent lack of delineation of the role of generalist service providers, and the absence of a strategic approach were seen as barriers to mainstreaming. Generalist service providers have been reluctant to add HIV/AIDS education and prevention activities to already crowded agendas, and there has been a lack of training for generalist staff in some jurisdictions. In the development of mainstream services, access to the services, especially for marginalised groups, must be ensured. The Commonwealth, States and Territories must work to better define the concept of mainstreaming and to ensure that infrastructure and training exist to support its implementation. The conclusions and recommendations of the recent national review of family planning associations concerning the associations' role in service provision and training in sexual health will be of direct relevance to the Education and Prevention Program.

#### Recommendation 11

**It is recommended that the Commonwealth and the States and Territories clarify the definitions of 'mainstreaming' and 'broader sexual health context' and assist the integration of HIV/AIDS into mainstream programs where**

**this is appropriate. This integration must be supported by a clear understanding of roles and responsibilities and adequate staff training.**

A related issue is use of dedicated HIV/AIDS resources for a broader range of communicable diseases. In most jurisdictions health departments' HIV/AIDS administration has been amalgamated with the administration of communicable diseases. A big advantage of this approach is the recognition of the close relationship between education and prevention strategies for HIV and strategies for other communicable diseases. This has allowed the development of more comprehensive control strategies—for example, Aboriginal and Torres Strait Islander programs for a range of STDs (including HIV); needle and syringe exchange programs and education for injecting drugs users about a number of blood-borne pathogens; and infection-control protocols for HIV, hepatitis B and hepatitis C. Although this approach is supported and should continue, monitoring is necessary to ensure that our response to HIV/AIDS is not compromised and that resources are not diverted from priority groups.

#### **Recommendation 12**

**It is recommended that HIV education and prevention continue to be incorporated in broader communicable disease approaches at the Commonwealth and State and Territory levels. Accountability mechanisms should exist to ensure that our response to HIV/AIDS is not compromised.**

### **4.12.2 Program design**

#### **Peer education and community development**

Peer education and community development have been the key strategies used in the Education and Prevention Program but the evidence of their efficacy is not well developed. Project evaluations of these strategies for a wide range of groups—gay men, other homosexually active men, sex workers, injecting drug users and disadvantaged young people—suggest that they are successful in reaching peer group members who may not be reached by other means. There is, however, only limited understanding of best practice in program design and peer educator training and this sometimes leads to a haphazard approach based on the belief that the initiatives are useful in any circumstance. The assumptions underlying the programs' design require rigorous examination to ensure their appropriateness.

#### **Recommendation 13**

**It is recommended that the Commonwealth, in consultation with the Intergovernmental Committee on AIDS, initiate an independent evaluation of peer education and community development projects, with a view to developing best practice models.**

**Revision of guidelines**

During the current HIV/AIDS Strategy the need to revise the guidelines for safe practices has arisen. Examples are inconsistent messages about the relative safety of different sexual practices, the implications of viral load at different stages of HIV infection, the efficacy of decontamination of needles and syringes, and the use of negotiated safety as an HIV risk-avoidance practice among homosexually active men.

At times, revised messages have been provided to the community in inconsistent and confusing ways. The question of who has responsibility for revising safe practice guidelines in light of new scientific information and changed social practices must be resolved. The Commonwealth must ensure that revision and dissemination of changed educational messages occurs in a coordinated and timely fashion.

**Recommendation 14**

**It is recommended that the Commonwealth ensure that revision and dissemination of changed educational messages about safe practices occurs in a coordinated and timely fashion.**

# Reducing the impact— the Treatment and Care Program

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## 5.1 INTRODUCTION

### 5.1.1 Objective

The objective of the Treatment and Care Program of the National HIV/AIDS Strategy is

to improve the quality of the lives of those people living with HIV/AIDS through the provision of high quality, accessible and timely treatment, care, counselling and support in a cost effective manner. (Commonwealth of Australia 1993a, p. 24)

The Strategy describes a model of care for people living with HIV/AIDS (PLWHA) in Australia. The starting point is that ‘people with HIV retain the right to participate in the community without discrimination and have the same rights to comprehensive and appropriate health care, income support and community services as other members of the community’ (p. 10). The explicit assumption in the Strategy is that Australia’s mainstream health and welfare system should take primary responsibility for meeting the needs of PLWHA. For example, the first Strategy document says, ‘Where possible, services for people with HIV should be provided by existing networks to take advantage of geographical range, efficiency and integrated care’ (1989, p. 56). The second Strategy document says that the decision about whether or not there should be specialised, HIV/AIDS-specific services should be based on the prevalence of the disease and the local health service infrastructure.

Both Strategy documents acknowledge the need to encourage development and change in Australia’s existing health and welfare services so that the rights of PLWHA are accommodated. There is also recognition that the whole community stands to benefit from harnessing PLWHA’s energy and commitment, which has been evident since the earliest days of the epidemic in Australia.

Direct service provision for PLWHA is largely the responsibility of State and Territory governments, so the Treatment and Care Program of the National Strategy is most accurately seen as a time-limited initiative of the Commonwealth Government. The pattern of Commonwealth involvement to date has been one of direct, ‘hands-on’ intervention in the early days, followed by a gradual but deliberate stepping back, especially in recent years as the

epidemic has required less crisis management and more maintenance of effort. The second Strategy envisaged that between 1993–94 and 1995–96 there would be an attempt to focus more clearly on strategic planning for the mainstreaming of HIV/AIDS programs and activities (Commonwealth of Australia 1993a, p. 1).

This chapter reviews the model of care envisaged by the Treatment and Care Program, discusses how well the Program has been implemented, presents data on the Program effectiveness in reducing the personal and social impacts of HIV/AIDS, and examines how appropriate the Program is for the future.

### **5.1.2 The scope and method of analysis**

Appendix A outlines the evaluation method. Several points should be kept in mind when considering the material in this chapter. Assessments of the adequacy or otherwise of service provision are based on material collected through consultations and submissions and questionnaire responses from State and Territory governments. The analysis highlights points that were identified frequently and from a number of different sources. For example, consumers, service providers and government officials in most States and Territories identified care of people with AIDS-related dementia as an area of unmet need. But not all identified problems or successes are relevant to all States and Territories. As well, the information was collected at the end of the second year of a three-year Strategy and the Treatment and Care Program has continued to change whilst being evaluated.

The most difficult judgment to make is about the ‘big picture’—the adequacy of the Program in terms of the model of care envisaged by the Strategy. The conclusions presented here do not apply to all regions of all States and Territories at all times, although a coherent enough picture is available to suggest directions for Commonwealth policy making and to identify areas that State and Territory governments might consider as part of their future planning. The gaps in the data are also instructive for determining future directions in monitoring and evaluation.

### **5.1.3 The model of care**

HIV affects every aspect of the HIV-positive person’s life, creating a need for a broad range of services of different levels of intensity and in different locations. HIV affects the lives of many others, too: partners, families, friends and broader social networks. The model of care proposed in the Strategy involves the gamut of health services, from acute hospital care to emotional and practical support in the community. Because of the breadth and complexity of the HIV-positive person’s needs, and the probability that a large number of care givers (professional and non-professional) may be involved at any particular time, the concept of a ‘continuum of care’ is central to the model of care as envisaged. A continuum of care has been defined thus:

## MONDAY LUNCH CLUB

In the Lizard Lounge of the Exchange Hotel in Darlinghurst, inner Sydney, the curtains are drawn, candles flicker, the room is reverberating to the strains of a singer-musician, and the audience is rapt.

This is top-quality entertainment in the heart of swinging Sydney, but it's only one o'clock on a Monday afternoon! The occasion is the weekly gathering of the Luncheon Club AIDS Support Group, a volunteer-run enterprise that each Monday brings together up to 200 people who are affected in some way by HIV/AIDS.

According to its founder, Carole Ann King, Luncheon Club patrons comprise people living with HIV/AIDS, their families, friends, lovers, carers, doctors and researchers—a microcosm of the people whose lives have been touched by the virus. The luncheon is free, with volunteers providing the food and service. These include elderly women, a few off-duty nuns and priests, mums and dads, young people—in all, an extremely diverse range of people. Spearheading the arrangements is chief cook and organiser, Carole Ann King, who began the luncheons because she felt guilty she did not have HIV.

'I had so many friends in the gay community in Sydney and as they began to die from AIDS I was in despair,' she explained. 'Why is this happening to such good people?' A single mother, Carole Ann said she experienced hideous multiple grief and realised there was nowhere for her, as an affected person but not an HIV-positive person, to go for solace.

After frequently visiting a day centre for people living with HIV/AIDS, she decided to hold a luncheon where people could come to focus on life, not death. It was so successful the Monday lunch has become a tradition with the affected community.' In just 18 months we have served over 20 000 meals, including home-delivered meals, with the support service, which in all has become a seven-day-a-week operation with no government or other funding,' she said.

'The Luncheon Club is a safe environment where, for a few hours a week, people can come together to care, share and support one another to live with AIDS, not die from AIDS. We can smile, laugh, not talk about death, illness or medication. For example, at last week's lunch we had lost three people to AIDS, but you would never have known it—it wasn't discussed or dwelt on—there was an unspoken common bond.'

Carole Ann said the greatest value of the Luncheon Club is that it is not only for people living with HIV/AIDS but also for those affected by it. 'We even have children along and run special events for them during the school holidays. Of the 30 children who come regularly, 18 would be HIV positive and the others are either their relatives or friends close to them,' she said.

Carole Ann is herself surviving on the dole so she has to use all her persuasive powers to enlist donations or goods and services to raffle to raise funds for the luncheons. 'What we particularly need is some funding for our own venue so as to extend our existing services to seven days and seven nights a week, with the inclusion of a food and clothing store for people living with AIDS who find it difficult to survive on the pension,' she said.

an integrated, client-oriented system of care composed of both services and integrating mechanisms that guides and tracks clients over time through a comprehensive array of health and social services spanning all levels of intensity of care. (Evashwick 1987, cited in AFAO, Submission 56)

Other key features of the model of care are as follows:

- There should be a balance between specialist and generalist services based on the prevalence of HIV and the existing health service infrastructure (Commonwealth of Australia 1993a, p. 1), an appropriate mix of inpatient and community care, and a balance between government and non-government services (p. 26).
- People with HIV have a right to be involved in planning and implementing treatment and care programs (p. 25).
- Volunteer services should be encouraged and supported as an integral part of the community care network (1989, p. 62). The second Strategy says that planning and resourcing at the State and Territory level will be needed to enable the gay community to maintain volunteer services in the face of an increasing number of its HIV-positive members progressing to AIDS.
- Early intervention, health maintenance and health monitoring should be encouraged (1993, p. 27).
- Continuing training of medical practitioners, nurses and other health care providers is essential because of the rapid developments occurring in HIV medicine and the specialised nature of HIV-related conditions and treatments (1989, p. 59).

Other treatment and care problems the Strategy said would be tackled are barriers to GP involvement in HIV medicine, the need to monitor tuberculosis and HIV, the need to develop a strategic and feasible approach to the provision of new HIV/AIDS therapies, the need to minimise HIV-related discrimination, and the need to develop methodologies and systems to monitor service use by PLWHA and the cost of the services.

The Strategy endorsed the growing role of sexual health clinics and said that role should continue to be strengthened in the areas of prevention, surveillance, HIV diagnosis, and care and treatment.

## **5.2 PROGRAM IMPLEMENTATION**

### **5.2.1 Inpatient care**

As described in Chapter 3, the Commonwealth provides earmarked funds under the Medicare agreements with State and Territory governments as a contribution towards the cost of inpatient services for AIDS patients. Table 5.1 shows payments to the States and Territories for the first two years of the

second Strategy and the projected payments for 1995–96. Approximately \$175 million will be provided to State and Territory governments for inpatient care in the three years of the Strategy. Medicare Hospital Funding Grants for AIDS constitute a small proportion of total Commonwealth Medicare Hospital Funding Grants to the States and Territories. In New South Wales, however, the proportion is more than double that of any other State or Territory because of the disproportionate share of AIDS cases in that State.

Under the Medicare agreements, the States and Territories are not required to report on the Medicare Hospital Funding Grants for AIDS beyond a statement of acquittal to the effect that the funds have been spent for the purpose for which they were intended. The States and Territories may include projects funded from Hospital Funding Grants in their project register reports to the Commonwealth but this is not done consistently and comprehensively. At the Commonwealth level there is no mechanism for determining whether the funds have been used for the priorities identified in the Strategy. Nor is it possible to link consumers' views about the quality of service delivery in any particular State or Territory back to the way the funds were administered within the particular hospital system. Data on hospital admissions suggest that there is wide variability in hospital utilisation between States and Territories.

**Table 5.1 Medicare Hospital Funding Grants for AIDS and total Medicare Hospital Funding Grants, by State and Territory, 1993–94 to 1995–96**

(\$million)									
Grants	NSW	Vic	Qld	WA	SA	Tas	NT	ACT	Total
1993–94 AIDS	31.7	9.9	4.9	2.3	2.8	0.3	0.2	0.8	52.8
Total HFG	1 367.4	1 006.0	784.6	489.3	440.1	120.5	76.9	64.2	4 349.1
1994–95 AIDS	31.7	10.2	5.8	2.5	3.0	0.4	0.2	0.9	54.7
Total HFG	1 447.3	1 023.8	818.8	505.6	456.1	122.9	75.6	67.5	4 517.6
1995–96 est. AIDS	42.6 <sup>a</sup>	10.8	6.5	2.8	3.4	0.4	0.2	0.9	67.6
Total HFG (June 1995 determination only)	1 499.4	1 058.1	864.9	492.8	469.0	136.4	79.3	69.2	4 669.1
AIDS Grants as percentage of total Medicare Hospital Funding Grants									
1993–94	2.32	0.98	0.62	0.47	0.64	0.25	0.26	1.25	1.21
1994–95	2.19	1.00	0.71	0.49	0.66	0.33	0.26	1.33	1.21
1995–96 (est.)	2.84	1.02	0.75	0.57	0.72	0.29	0.25	1.30	1.45

a. Includes \$4.0 million from 1994–95.

Source: Commonwealth of Australia (1995).

## 5.2.2 Outpatient care and care in the community

The Treatment and Care grants under the Matched Funding Program are intended for projects that provide support services for PLWHA, their partners, families, friends and carers. They include counselling, palliative care, outreach,

home care, ambulatory care, hospice care, day care, and outpatient and STD services. A proportion of the funds may also be directed towards evaluation and coordination of HIV-related services. It is not intended that the Matched Funding Program include inpatient hospital services (since these are funded under the Medicare Hospital Funding Grants) or education and training. Table 5.2 shows that a combined Commonwealth, State and Territory total of \$24.560 million was spent during 1993–94 on treatment- and care-related projects. New South Wales expenditure accounted for over 76 per cent of the total, although this overestimates the New South Wales share of total Treatment and Care Program expenditure because some projects receiving funds from the Medicare Hospital Funding Grants for AIDS complete project register returns while this practice is not as common in other States and Territories.

**Table 5.2 MFP Treatment and Care Program expenditure and number of projects, by State and Territory, 1993–94**

State/Territory	Expenditure (\$'000)	Proportion of total expenditure (%)	No. of projects	Average project expenditure (\$)
NSW	18 820	76.7	136	138 382
Vic	3 048	12.4	30	101 600
Qld	794	3.2	18	44 111
WA	778	3.2	10	77 800
SA	637	2.6	13	49 000
Tas	102	0.4	4	25 500
NT	187	0.8	5	37 400
ACT	194	0.8	6	32 333
Total	24 560	100.0	222	110 631

Source: Commonwealth of Australia (1995).

The following sub-sections on care in the community deal either with those specific things that the first and second Strategies said should happen in this area or with aspects of care and support that emerged during the evaluation as requiring additional attention. It is not an exhaustive account of every aspect of the Treatment and Care Program.

### **The balance of care**

Nearly 64 per cent of Matched Funding Program treatment and care projects were based in or auspiced by government agencies; this compares with 36 per cent based in or auspiced by non-government agencies (see Table 5.3). The non-government sector has increased its share of the total number of projects auspiced from just over 8 per cent in 1992–93. Inpatient care accounts for the majority of resources in the Treatment and Care Program. This conclusion is corroborated by the data on the cost of treating HIV reported in Section 5.3.1.

Table 5.4 reports expenditure by the type of organisation receiving funds under

**Table 5.3 MFP Treatment and Care projects and expenditure: government and non-government organisations, 1993–94**

Provider	No. of projects (per cent)	Expenditure (\$'000) (per cent)
Government	142 (64)	19 770 (80)
Non-government	80 (36)	4 790 (20)
Total	222 (100)	24 560 (100)

Source: Commonwealth of Australia (1995).

**Table 5.4 MFP Treatment and Care expenditure, by type of organisation, 1993–94**

Organisation	No. of projects (per cent)	Expenditure (\$'000) (per cent)
Hospital	50 (23)	13 310 (54)
State/Territory health authority	15 (7)	390 (2)
Regional health authority	1 (0)	20 (0)
Alcohol and drug agency	4 (2)	90 (1)
AIDS/STD clinic	49 (22)	3 818 (15)
Other government	10 (5)	172 (1)
Community health centre	26 (12)	1 714 (7)
Commercial enterprise	1 (0)	12 (0)
Non-profit organisation	44 (20)	3 181 (13)
Affected community	20 (9)	1 836 (7)
Other community group	2 (1)	18 (0)
Total	222 (100)	24 560 (100)

Source: Commonwealth of Australia (1995).

the Matched Funding Program for 1993–94. Hospitals account for the largest share of funds, presumably through the provision of outpatient services or through their role as auspice bodies for services provided by sexual health clinics. A 'project' may vary enormously in size. Some attract funding of a few thousand dollars while others may be allocated as much as \$2 million. For example, the outpatients clinics at St Vincent's and Royal Prince Alfred Hospitals in Sydney between them accounted for \$3.3 million in Matched Funding Program funds in 1993–94.

### Volunteer services

Some services funded under the Matched Funding Program rely on the labour of volunteers. Data provided to the evaluation by a number of the large agencies involved in providing volunteer services in a number of States and Territories suggest that, on average, a person with HIV/AIDS and in receipt of volunteer services receives between 50 and 100 hours of direct volunteer care and support each year.

AIDS councils in New South Wales and Victoria report severe pressure on their volunteer services: the causes would seem to be exhaustion of the available pool of volunteers and the growing demand resulting from increased numbers of AIDS cases. Volunteer services in other States and Territories do not report similar pressure at present, but they have less mature epidemics. Haemophilia Foundation Australia has identified an important need to consider more assistance for carers, especially those who are primary carers of people with HIV/AIDS.

The Strategy asks State and Territory governments to deal with this problem through planning and resourcing. Volunteer services play a critical role in maintaining people in the community, so more attention should be given to supporting them.

At the Commonwealth level there are insufficient data to determine whether there was any change in the level of resourcing of the volunteer sector in the second Strategy compared with the first Strategy.

#### **Recommendation 15**

**It is recommended that State and Territory treatment and care plans ensure the continuing viability of community-based volunteer services and pay closer attention to the needs of carers.**

#### **Health maintenance and monitoring**

The second Strategy is said to be conceptually weak because of its concentration either on the education of those who are HIV negative or on the treatment of those with advanced HIV/AIDS. The needs of those who are HIV positive but asymptomatic are thought to receive insufficient attention (AFAO, Submission 56).

As noted in the discussion of PLWHA in Sections 2.3 and 5.3.1, there are substantial health and economic benefits associated with early intervention in the treatment of HIV.

Health maintenance and monitoring are currently the focus of several projects. At the national level, a large health maintenance and monitoring project has been funded through the National Education Program managed by the AIDS/Communicable Diseases Branch of the Department of Human Services and Health. AFAO also receives funding for a National Treatments Project, which provides information on treatments to both consumers and service providers. An analysis of the project register data for 1993–94 shows that there were 27 instances of projects claiming health maintenance as part of their service provision.

PLWHA have a valuable contribution to make in policy development and service delivery in this area and should be included in relevant decision-making and planning processes at the national and State and Territory levels.

**Recommendation 16**

**It is recommended that health maintenance and monitoring be included in a third National HIV/AIDS Strategy and in State and Territory treatment and care plans.**

**HIV testing**

The general population has access to testing for HIV through GPs, sexual health clinics, community health centres and hospitals. Funding for testing is provided by the Commonwealth and the States and Territories through the Matched Funding Program.

A significant number of the submissions to the evaluation reported that pre- and post-HIV test counselling is inadequate for some groups and in some parts of Australia. Breaches of confidentiality persist as a major source of complaint to AIDS organisations. These problems appear to be exacerbated in small communities. There is also considerable doubt about the extent to which routine antenatal HIV screening and pre-surgery screening is accompanied by appropriate counselling. These problems are part of wider difficulties that are associated with testing for blood-borne pathogens.

**Recommendation 17**

**It is recommended that the Australian National Council on AIDS and the Intergovernmental Committee on AIDS review current arrangements for pre- and post-HIV test counselling and identify sustainable, long-term measures to ensure that service providers are trained to undertake risk-factor assessment and counsel patients in an appropriate manner. This should be combined with work to improve testing procedures for all blood-borne pathogens.**

A guiding principle of the Strategy is that specific informed consent should be obtained before any test, that results should remain confidential, and that appropriate pre- and post-test counselling should be provided. In 1994 the IGCA agreed that the following principles should guide Australia's approach to HIV testing:

- Testing should be voluntary and confidential and should include counselling.
- Testing should be of the highest possible standard.
- Testing is to be accessible for those at highest risk of HIV infection.
- Testing policy is critical to determining the extent and location of HIV infection in the community.

There is broad consensus that the current testing structure supports these principles and that it has made a very important contribution to the overall success of the Strategy. There are, however, pressures for change in relation to

## POSITIVELY ALIVE

When Mark Counter, a high-flying super sales manager for a cosmetics company, discovered he had a lump under his arm he became alarmed.

He went to the local doctor, fearing the worst—cancer. After some blood tests the doctor blandly told him: 'The good news is you don't have cancer. The bad news is you've got AIDS and you're going to die anyway.'

Leaving the doctor's rooms 10 years ago, Mark recalls the feeling of utter devastation.

'They didn't know much about HIV in those days so I was given no information, no brochures, no counselling, no back-up—just a death sentence,' he said.

'I didn't tell anybody. I knew what people thought about AIDS in those days—nobody understood how it was transmitted, whether they could catch it from touching or from drinking from the same cup as an HIV-positive person.

'I basically alienated myself from people. I could not accept my diagnosis—it was all too hard to take in.'

Mark didn't mention his HIV-positive status to many people in the cosmetics company and he went on to accept a job with even more responsibility as general manager for a large company.

'I had taken a pragmatic approach—I was not feeling ill and, although I practised safe sex from then on, I was in a sort of denial, and went on living my life as normally as possible.

'It wasn't until about a year and half after diagnosis that I decided that being HIV positive wasn't going to get me down. I worked at the same frantic pace for another five or six years, living a sort of Dr Jeckle and Mr Hyde existence,' he said.

'Eventually my doctor (a specialist in HIV medicine) suggested that my stressful workload was becoming detrimental to my health and could speed up my illness. I decided I would need to give up work and start a new life.

'This was a devastating change of pace for me—I gave up an entire lifestyle, a penthouse, company car and huge salary to literally exist on the dole.'

Mark moved into a house he owned on the Gold Coast in Queensland and did some soul-searching about living with HIV.

'I had a good cry for the first time and this was good for me,' he said.

Today, Mark is one of the most high profile HIV/AIDS community activists. He is the Convenor of the National Association of People Living with HIV/AIDS and works full time as a policy adviser at the Queensland AIDS Council.

'Being HIV-positive can be quite releasing and empowering—you get on with the things that are really important when you know you could be dead in six months,' he said.

the perceived excessive testing in low-risk populations, the number of laboratories able to test for HIV, and the availability of new technology.

The Commonwealth and State and Territory governments agree that the current level of testing in low-risk populations is excessive. Because testing is funded under the Matched Funding Program, increases in the number of HIV tests conducted directly affect State and Territory budgets and either reduce the amount that can be spent on other HIV programs or cause the States and Territories to spend more on HIV/AIDS programs than they otherwise might. All agree that measures to control the rate of inappropriate testing in low-risk populations are desirable.

In submissions to the evaluation several State and Territory governments expressed the view that HIV testing should be put on the Medicare Benefits Schedule. The IGCA's preferred position is similar. But the Commonwealth is opposed to this on the basis that the current system best satisfies the agreed HIV testing policy principles and is fundamental to the overall success of the Strategy. It also appears to have a restraining effect on the number of tests ordered while retaining access for those at highest risk of HIV infection.

Concern about the cost of HIV testing has caused some States to seek ways to reduce the total number of tests. Victoria has tested and evaluated an approach incorporating a user-pays component. The evaluation of the approach showed a disproportionate reduction in testing of high-risk populations and the approach was subsequently modified.

It is worth noting that the annual rate of increase for HIV testing is below the rate of increase for all pathology testing. Since 1991 the rate of growth in HIV testing has been approximately 4 per cent and appears to be evening out. This compares with the rate of growth for services under category 6 of the Pathology Schedule of the Medicare Benefits Schedule, which was approximately 9.5 per cent in 1993–94 and 1994–95.

Limiting the number of laboratories able to test for HIV as a means of ensuring high-quality testing is less valid than it once was because of the greater availability and reliability of HIV test kits. In 1991 some private laboratories were approved to conduct HIV tests and by 1994 they had done over 134 000 tests. It could be argued that increasing the number of laboratories would improve access and shorten the time taken to report test results. There is, however, also potential for an increased level of testing for inappropriate purposes or without adequate counselling. Increasing the number of service providers would also probably increase the number of tests performed, which would affect the overall cost of testing.

The current HIV testing system was devised several years ago, when the overriding concern was to ensure that people engaging in high-risk behaviours had access to HIV testing so as to help reduce further transmission and facilitate access to early treatment intervention. It could be argued that the current

**Table 5.5 HIV/AIDS testing: all sources, 1985 to 1994**

Organisation	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994
Blood banks	417 760	796 515	918 171	939 984	969 652	991 626	980 953	983 927	949 293	903 131
Public health laboratories	47 207	89 592	354 605	365 622	503 386	706 971	733 717	738 012	711 046	613 128
Private laboratories	0	0	0	0	0	0	4 992	41 914	89 524	134 547
Total testing	464 967	886 107	1 272 776	1 305 606	1 473 038	1 698 597	1 719 662	1 763 853	1 749 863	1 650 806

Note: 1994 figures are not complete because not all laboratories are up to date with sending data.

Source: National HIV Reference Laboratory (1995).

**Table 5.6 Funding and number of tests for HIV/AIDS in Australian public health laboratories and private laboratories, by State and Territory, 1992 to 1995**

State/Territory	Funding (excluding bloodbanks)				Number of tests (excluding bloodbanks)		
	1992–93 MFP (\$'000)	Testing as per cent of MFP 1992–93	1993–94 MFP (\$'000)	Testing as per cent of MFP 1993–94	1992–93	1993–94	1994–95
NSW	2 322	5	4 466	10	329 328	317 954	295 924
Vic	1 364	14	1 586	16	139 621	139 844	101 189
Qld	441	8	609	11	138 712	123 209	140 870
WA	695	18	662	18	67 516	72 531	69 030
SA	754	19	734	19	77 439	86 797	32 391
Tas	-	-	-	-	12 089	13 490	13 053
NT	-	-	33	3	8 978	10 256	11 886
ACT	-	-	-	-	10 738	10 094	10 125
Total	5 576	8	8 091	11	784 421	774 175	674 468

Notes: 1994–95 figures are not complete, especially for 1995, because not all laboratories are up to date with sending data.

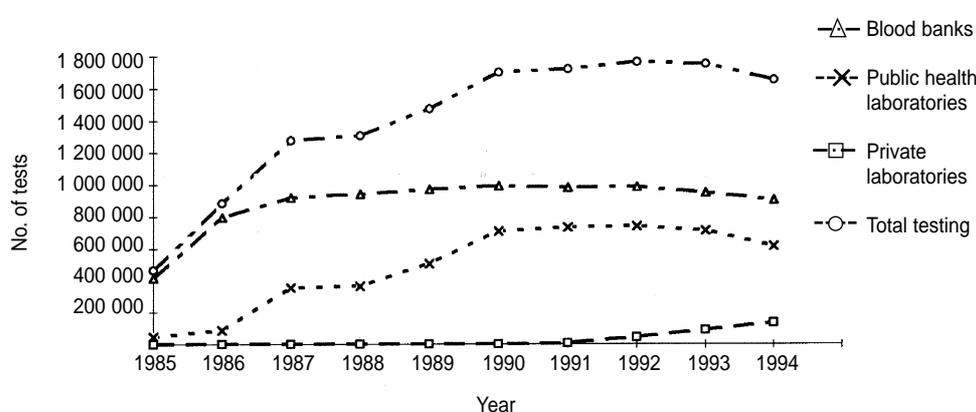
Differences in funding between 1992–93 and 1993–94 are principally due to changes in the project register data collection between those two years.

Testing includes a wide range of funding items, from testing infrastructure to effort devoted to pre- and post-test counselling. MFP figures are actual expenditures.

Source: Commonwealth of Australia (1995); IGCA (1994); National HIV Reference Laboratory.

system does not take into account new and emerging technologies such as viral load testing and rapid testing, including the use of alternative samples (saliva or urine). Changed technologies will enable tests to be performed outside laboratory settings and for health maintenance and monitoring. This presents challenges for the application of the principles that guide Australia's approach to HIV testing.

**Figure 5.1 HIV/AIDS testing: all sources, 1985 to 1994**



Note: 1994 figures are not complete because not all laboratories are up-to-date with sending data.

Source: National HIV Reference Laboratory (1995).

There is a continuing need to ensure that accurate diagnostic testing is accessible to those at greatest risk. New technology, the cost of testing and the number of laboratories all affect the capacity to do this. An ANCA working party is being established to review testing policy in light of these difficulties. The testing system must adapt over time and there should be mechanisms to enable the testing system to be refocussed when necessary.

### **Recommendation 18**

**It is recommended that the existing HIV testing policy framework be maintained, that the Intergovernmental Committee on AIDS continue to explore ways of reducing demand for testing in low-risk populations, and that the Commonwealth closely monitor the overall impact of an increase in testing on the Matched Funding Program.**

### **General practice**

General practitioners are integral to achieving the goal of maximising community care for PLWHA. The Strategy says, however, '... barriers to general practitioner participation in HIV medicine do exist and will be

investigated with a view to improving their involvement' (Commonwealth of Australia 1993a, p. 26). The Strategy does not identify who will be responsible for this investigation.

In the case of barriers created by a lack of skills among GPs, some measures have been taken during the second Strategy. As part of the Health Maintenance and Monitoring Project funded through the National Education Program, the Australian Society for HIV Medicine and the Royal Australian College of General Practitioners have been funded to conduct the National Education Project for Australian Doctors. This Project is designed to raise among GPs awareness of the need for them to develop basic skills in HIV medicine. Courses are also available for GPs to enable them to become competent practitioners of HIV medicine. For example, there is a GP training program in HIV medicine at Fairfield Hospital in Melbourne.

In the consultation workshops conducted during the evaluation, however, a shortage of GPs with skills in HIV medicine was said to be a problem to some extent in all States and Territories. It was described as a particular problem in rural and remote areas, but it is also a problem in some metropolitan areas. Part of the challenge of providing better health maintenance and monitoring services relates to the accessibility of adequately trained GPs. HIV-positive women need better access to gynaecological services provided by clinicians with training in HIV.

Consultations in South Australia and the Northern Territory identified problems with prescribing rights for GPs. In their submissions to the evaluation, AFAO and NAPWA identified prescribing rights as a concern for their members. Standards of care do need to be protected through proper accreditation, but the principles of equity and access are not being respected by current variability in accreditation practices. This is one of the matters that should be part of the process of developing '... a strategic and feasible approach to the provision of new HIV/AIDS therapies', which was one aim of the second Strategy (p. 28).

### **Recommendation 19**

**It is recommended that the Intergovernmental Committee on AIDS review variations in accreditation practices relevant to prescribing Highly Specialised Drugs Scheme treatments with a view to providing that principles of equity and access are maintained while providing a high standard of service delivery.**

One frequently stated barrier to GP involvement in HIV medicine is the low remuneration under the Medicare Benefits Schedule for extended consultations. It is plausible that quality care (including palliative care) for the HIV-positive person will involve a relatively large number of extended consultations. Other barriers need to be identified and discussed in a transparent fashion.

## GENERAL PRACTICE IN DARLINGHURST

Dr 'Robert' is a GP who has a private practice in the heart of inner-city Darlinghurst, widely regarded as the gay mecca of New South Wales.

Most of Robert's patients are gay men, many are HIV positive or are people seeking HIV testing. 'Of the gay men I see, about 25 per cent are HIV positive,' Robert said. 'They come to me in all stages of the disease, many of them having previously abandoned medical care because of the perceived hopelessness of treatments available.'

'I encourage people to take prophylaxis antibiotics to ward off PCP (*Pneumocystis carinii* pneumonia) infection. Many people, however, are taking AZT (a commonly used anti-HIV drug) and are looking for combination therapy which they know is more effective than AZT by itself. This is very difficult for me because unless their T-cell count is at a certain number and the disease is progressing, I can't legally prescribe a combination of medications and that's very frustrating for me and for the patient,' he said.

Robert is bitter about a lot of the bureaucratic red tape that he claims hampers the treatment of his patients. 'The Federal Government really stuffed up on AIDS patients when they brought in the new regulations to stop medical abuse of pathology tests,' he explained. 'It has had an unintentional and detrimental effect on AIDS patients who need a number of tests at various pathologists. It means they have to keep coming back and forth for more tests and some of them just don't bother in the end,' he said.

Robert's practice sees mostly men in the 25–35 age group who are either aware of their HIV status or regularly want to test to make sure they are OK. 'Most gay men, even though they practice safe sex, like to test every six to 12 months,' he said. 'I am seeing a lot more partners who have negotiated a sexual agreement coming in for tests. This agreement usually determines that if either party has sex outside their relationship, they will always use a condom. Inside the relationship they do not. It's a risky agreement based on trust, but something that gay men are embracing a lot more,' he said.

Robert said, despite a commitment to safe sexual practices, where emotions and passions are involved there will always be slip-ups. 'Some HIV-positive men think that if a new partner does not suggest a condom, that the other person is also positive. Others think the reverse.'

Robert also works with homeless young people. 'They are of great concern,' he conceded. 'The girls don't even practice safe sex for contraception, let alone HIV or other STDs.'

Robert is thankful for open-door clinics like Kirkton Road and Albion Street in Sydney, both places where he has previously practised. 'They have made a huge contribution to the containment of HIV in New South Wales and been a life saver for many men and women in our community,' he said.

**Recommendation 20**

**It is recommended that the Commonwealth take responsibility for reviewing barriers to general practitioners' involvement in HIV medicine and include measures to overcome these in a third Strategy.**

**Intermediate care**

Consultations and submissions identified intermediate care as part of the continuum of care that is not given adequate attention. Intermediate care is required when inpatient care is too intensive for the needs of the person but care in the community is not viable. Variations in this type of care are referred to as 'step-down care' or 'supported accommodation'. Nursing homes and hostels are the main response to this problem among the aged. But PLWHA have very different care needs and nursing homes and hostels are not appropriate for younger people. Innovative ways of dealing with this problem are needed. Some States and Territories are seeking to deal with it—for example, South Australia has recently done a study of the feasibility of establishing a small step-down care facility.

**Recommendation 21**

**It is recommended that State and Territory governments give consideration to the need for intermediate care in the development of their treatment and care plans.**

**Mental health**

HIV/AIDS creates a range of mental health needs. Many projects funded under the Matched Funding Program report providing counselling services. During the evaluation a number of areas of unmet need were identified: the need of newly diagnosed HIV-positive people for support and the development of self-esteem; the needs of long-term HIV-positive people who have lived long past predictions of their own death; the need for counselling services for people of non-English-speaking background; the needs of the chronically mentally ill who are HIV positive; and the needs of people with AIDS-related dementia.

As noted in Chapter 2, AIDS-related dementia is primarily a late manifestation of AIDS and is probably increasing in prevalence as prophylaxis for other AIDS-related illnesses improves. It has a severe impact on the quality of life of PLWHA and their carers. Community support teams are placed under great strain and respite care is very difficult to find. Institutional care options are very limited: acute care wards are not able to cope satisfactorily and mental health and dementia care facilities for the elderly are inappropriate. There are also legal questions associated with the cognitively impaired that need resolution. The New South Wales Health Department reports that considerable work on this problem has been done and an appropriate accommodation facility is being planned.

**Recommendation 22**

**It is recommended that State and Territory governments include mental health services as an integral part of their treatment and care plans. The Intergovernmental Committee on AIDS should undertake a needs assessment and identify possible solutions applicable to AIDS-related dementia.**

**Dental health**

Gum disease is a common problem in the late stages of HIV/AIDS. It can affect the quality of life of PLWHA and exacerbate difficulties with maintaining adequate nutritional status. Early intervention and treatment can mitigate these problems. Dental care should be included in treatment protocols for HIV/AIDS patients.

Problems with access to dental health care were raised during consultations and in a number of submissions to the evaluation. Although the Commonwealth Dental Health Scheme has worked well in improving access, the limit of \$440 worth of treatment each year is reported to be too low for the dental health needs of PLWHA. There were also reports of major access problems with the Scheme in some States and Territories, especially Queensland. South Australia apparently now has an excellent dental clinic for PLWHA.

Discriminatory attitudes and ignorance of the role of dental health in the management of HIV are reported to be a significant continuing problem. To redress this, the Commonwealth has funded through the National Education Program a project aimed at dentists. It deals with discrimination in relation to HIV/AIDS and other blood-borne pathogens, is national in scope, and has been developed in consultation with relevant professional bodies.

**Recommendation 23**

**It is recommended that a third National HIV/AIDS Strategy specifically acknowledge the importance of dental care in treatment protocols for people with HIV/AIDS. State and Territory treatment and care plans should include an assessment of the adequacy of dental health care for people living with HIV/AIDS.**

**Pharmaceuticals**

People living with HIV/AIDS have access to subsidised pharmaceuticals via the Pharmaceutical Benefits Scheme and via the Highly Specialised Drugs Scheme under s. 100 of the *National Health Act 1953*. The Schemes are not specific to HIV/AIDS: pharmaceuticals are available to all Australian residents under both of them. Under the Pharmaceutical Benefits Scheme, subsidised pharmaceuticals are available from community pharmacies on prescription from a GP or

specialist. Under the Highly Specialised Drugs Scheme, pharmaceuticals that are costly and highly specialised are provided through hospital pharmacies and are paid for jointly by the Commonwealth and the State or Territory government concerned—the Commonwealth pays for the proportion of use associated with the treatment of outpatients. GPs who are accredited may prescribe pharmaceuticals from the Highly Specialised Drugs Scheme but the pharmaceuticals themselves are available only through hospital pharmacies.

Six of the 13 drugs listed on the Highly Specialised Drugs Scheme are for AIDS-related conditions. Expenditure on these drugs in 1993–94 was \$6.4 million, which represented 14.4 per cent of total Scheme expenditure.

Problems connected with the availability of pharmaceuticals were raised by both consumers and service providers, including NAPWA, AFAO and the Australasian Society for HIV Medicine. Reform of the drug approval system following the Baume report is acknowledged to be an important advance, but there continues to be concern about a number of things: the complexities of drug funding and the cost-shifting between State and Territory governments and the Commonwealth; the problems PLWHA have in gaining access to hospital pharmacies (Kay 1994, p. 32), especially in rural areas; the time taken between approval of new treatments and the finalisation of financing arrangements; the variations in the amount of compassionate access for different treatments; and problems with doctors not knowing which pharmaceuticals are available on a compassionate basis.

The Australian National Audit Office has engaged Deloitte Touche Tohmatsu to review during the next 12 months the implementation of the Baume report. More immediately, the Commonwealth Department of Human Services and Health's Audit and Payments Branch is reviewing the approvals process and s. 100 listing of pharmaceuticals; it will report to the Federal Minister for Health late in 1995.

#### **Recommendation 24**

**It is recommended that the Australian National Council on AIDS ensure that the proposals resulting from the reviews of implementation of the Baume report, the approvals process and the listing of pharmaceuticals under s. 100 of the *National Health Act 1953* be examined and, as appropriate, implemented as a matter of urgency.**

#### **Clinical trials**

The subject of clinical trials came up repeatedly during consultations on the Treatment and Care Program. Clinical trials are used by PLWHA as a way of gaining access to new, potentially more effective treatments in an area where advances in treatment have been disappointing. This brings with it two complications: it has resulted in a reassessment of traditional clinical trial methodologies that use controls; and it has led to an expectation that when the

trial finishes people will continue to have access to drugs they may have found beneficial and that government will pay.

Although the work of the National Centre in HIV Epidemiology and Clinical Research and the Community HIV/AIDS Research Network has led to significant improvements in the management of clinical trials for the benefit of PLWHA, a number of problems remain, among them the lack of access for those PLWHA in non-metropolitan areas and the need for further research on treatments specific to the needs of HIV-positive women.

These and other matters related to clinical trials are being dealt with through the development and implementation of the National HIV/AIDS Treatments Strategy by the Clinical Trials and Treatments Advisory Committee.

### **Involving PLWHA in decision making**

The National HIV/AIDS Strategy says that people who are HIV positive have a right to be involved in the planning and implementation of treatment and care programs. It is difficult to determine the extent to which this right has been realised.

At the individual level, much effort has been made to enable PLWHA to take control of their own health. This has been done by PLWHA organisations, at times supported by government-funded projects. For example, the AFAO National Treatments Project has a booklet entitled *Your Doctor and You: a guide for people with HIV/AIDS to monitor their health in a partnership with their doctor*. There are also peer support groups and positive living centres run by PLWHA; these meet a range of needs.

At the institutional level, PLWHA organisations are seeking greater control over resources devoted to helping their constituents and greater resources to support their activities. The role of these organisations and their relationship with AIDS councils appear to vary between the State and Territories. NAPWA submitted to the evaluation that resources for peer education and long-term support and self-help programs should be gradually transferred from AIDS councils to PLWHA. It also stressed a high degree of frustration felt by PLWHA when working with AIDS councils.

The Commonwealth should continue to be supportive of the involvement and empowerment of the affected communities but it should not be prescriptive about which organisations should take on what role at the local level when providing services to PLWHA. The principle of empowerment should be considered alongside the need to ensure cost-effective, high-quality, accessible and timely service provision when services are being planned at State and Territory and local levels.

The frustration expressed by NAPWA at what it perceives as its continuing client status within AIDS organisations should be a matter of concern to the Commonwealth, State and Territory governments, and AIDS councils.

**Recommendation 25**

**It is recommended that the Commonwealth, the States and Territories, and non-government organisations support the role of people living with HIV/AIDS in treatment and care.**

**The continuum of care**

The Strategy says that the concept of a continuum of care should guide the development of the service delivery system for PLWHA. As noted, this essentially relates to the capacity of the parts of the health system (hospitals, GPs, community care teams, and so on) to work together so that people are not lost between levels of care or types of services. Application of this concept is not unique to HIV/AIDS: it is currently a focus of health policy development at the national level through the Council of Australian Governments.

Consultations and submissions suggested that there are sometimes problems with coordination and cooperation between volunteer community care teams and the professional community care sector. There were also reports of problems with discharge planning and of hospitals not communicating well with GPs or the community care network. Communication between specialists and GPs is also not as good as it could be. It is not possible to estimate how widespread these problems are.

One way of ensuring a continuum of care is by using case management, where responsibility for coordinating a complex plan of care is taken by one care provider. Nurses are often called on to play this role, among many other roles, in the care of PLWHA. Given the importance of the continuum of care concept and the multifaceted nature of the care often required by PLWHA, State and Territory governments should consider the need for case management in treatment and care service planning.

**Recommendation 26**

**It is recommended that, as part of the development of State and Territory treatment and care plans, the capacity of the system to deliver a continuum of care be considered and the development of case management strategies be explored.**

**5.2.3 Specific implementation matters****Treatment and care services for Aboriginal and Torres Strait Islander people**

Very little expenditure under either the Matched Funding Program or the Special Funding Program goes toward HIV/AIDS treatment and care of Aboriginal and Torres Strait Islander people. This is at least partly due to the small number of cases. It is also due to the practice of reporting expenditure on Aboriginal and Torres Strait Islander sexual health workers as 'education and prevention' expenditure whereas at least part of their role is more accurately

described as ‘treatment and care’. Treatment and Care Program expenditure under the Special Funding Program in 1993–94, as reported in the project register, was \$66 000 (excluding Queensland data, which were not available).

There are reports of HIV-positive Aboriginal and Torres Strait Islander people having difficulty obtaining appropriate treatment and care. Injecting drug users and homosexually active men fear discrimination in their communities because of a lack of acceptance of their lifestyle. They also do not feel accepted by HIV/AIDS services because of their Aboriginality. Aboriginal and Torres Strait Islander education programs should continue to aim to build understanding and support for HIV-positive people within their communities. Both mainstream and Aboriginal and Torres Strait Islander health services need to make ready for an increase in the number of cases of HIV/AIDS and tuberculosis among Aboriginal and Torres Strait Islander people.

A number of strong and consistent messages emerged from consultations with indigenous communities:

- HIV/AIDS/STD treatment and care services cannot be based on an assumption that the existing health service infrastructure is adequate. Although HIV/AIDS is a spectre haunting the future of Aboriginal and Torres Strait Islander health, there are already present in indigenous communities epidemics that cause preventable sickness. STDs are a prime and worrying example because of their capacity to facilitate HIV transmission.
- HIV/AIDS and STDs are culturally sensitive subjects and must be managed in a way that respects cultural values. The enormous diversity of Aboriginal and Torres Strait Islander communities means that approaches and solutions simply cannot be transported from one area to another and expected to work.
- HIV/AIDS/STD services cannot be developed and delivered in isolation from other Aboriginal and Torres Strait Islander health services, nor can they be separated from the wider political and cultural context of Aboriginal and Torres Strait Islander people’s struggle for self-determination. Indigenous communities are demanding a partnership with government that spans the policy development cycle, from needs assessment based on data collection and analysis, through planning and program implementation to monitoring and evaluation. Parallels can be drawn with the effective partnership the gay community developed with government at all levels during the Strategy’s development.

Because of the probability of a large increase in the number of cases of HIV/AIDS and tuberculosis in Aboriginal and Torres Strait Islander communities, the current state of medical preparedness must be assessed thoroughly and as a matter of urgency. This should be done in partnership with Aboriginal and Torres Strait Islander community representatives, taking full

account of the work of the Office for Aboriginal and Torres Strait Islander Health Services within the Department of Human Services and Health and in liaison with the ANCA Working Party on Aboriginal and Torres Strait Islander Sexual Health. One matter that requires particularly urgent attention is the development of protocols for managing positive HIV test results, especially in relatively small communities. Community-based care must be enhanced through measures to develop greater acceptance of HIV-positive Aboriginal and Torres Strait Islander people across all health services and in their own communities.

**Recommendation 27**

**It is recommended that the Intergovernmental Committee on AIDS, in consultation with the Office for Aboriginal and Torres Strait Islander Health Services and the Australian National Council on AIDS Working Group on Aboriginal and Torres Strait Islander Sexual Health, develop an Aboriginal and Torres Strait Islander HIV/AIDS and Tuberculosis Medical Preparedness Action Plan.**

In light of the new arrangements for the administration of Aboriginal and Torres Strait Islander health policy at the Commonwealth level, consideration should be given to whether or not the Special Funding Program should continue as an HIV/AIDS/STD-specific program or be included in some larger funding program administered through the Office for Aboriginal and Torres Strait Islander Health Services.

In the short term, the current administrative arrangements should continue to allow processes that have been initiated since the funds first became available in 1993–94 to come to fruition. Keeping HIV/AIDS/STDs as a separate issue serves to highlight its relative importance. It will also allow time for the new Commonwealth arrangements to consolidate and for consideration to be given to the most appropriate way to integrate the services.

Continuation of the Special Funding Program should be contingent on State and Territory governments improving their performance in building partnerships with Aboriginal and Torres Strait Islander communities through meaningful consultation and developing substantive strategic plans for dealing with HIV/AIDS/STD. It is appropriate for some Special Funding Program funds to be used to help with the process of developing strategic plans, as has been the case in the Northern Territory.

**Recommendation 28**

**It is recommended that a third National HIV/AIDS Strategy increase funds for HIV/AIDS/STD initiatives directed at Aboriginal and Torres Strait Islander people. If necessary, the increase in resources should be gradual to allow adequate time for consultation and planning.**

**Recommendation 29**

**It is recommended that the Commonwealth revise the guidelines for the Special Funding Program. The new guidelines should explicitly require, as a condition of funding, that State and Territory governments consult with Aboriginal and Torres Strait Islander communities and develop comprehensive strategic plans for the use of funds. The plans should take account of the need to improve the collection of surveillance data and identify how data will be collected, analysed and used in partnership with Aboriginal and Torres Strait Islander health services.**

**HIV-positive women**

Consultations and submissions to the evaluation suggest HIV-positive women have important areas of unmet need. Treatment information for women is particularly lacking. The continued exclusion of women from clinical trials means that information about the effects of specialised AIDS drugs on women is almost non-existent. HIV-positive women's health has been regarded almost wholly in terms of a woman's ability to transmit the virus to the foetus or through breast milk. HIV-positive women may also face difficulties with child care, with the fostering of their children during periods of ill health, or with adoption in the long term.

The number of HIV-positive women is relatively small and AIDS services frequently focus on the needs of HIV-positive men. It might be appropriate to consider what arrangements can be made through women's health services to cater more effectively for the needs of this group.

**Recommendation 30**

**It is recommended that State and Territory treatment and care plans include an assessment of HIV-positive women's needs for peer support and their specialised health and social needs.**

**Complementary therapies**

Complementary therapies, such as Chinese medicine, homeopathy, naturopathy and herbalism, are often used by PLWHA (Arachne 1995). The first National HIV/AIDS Strategy recommended that practitioners of 'alternative' therapies publish studies in peer-reviewed journals so that consumers can make informed choices. Some research is being done but the quality of that research needs careful scrutiny. The popularity of complementary therapies and the fact that they are used in conjunction with 'orthodox' treatment (either with or without the knowledge of the 'orthodox' doctor) raises questions about the role of government in facilitating research in this area. Two areas of investigation are warranted: therapies for which there is evidence of beneficial effect for PLWHA; and therapies for which there is concern about potentially dangerous interactions with 'orthodox' treatments.

**Recommendation 31**

**It is recommended that the Australian National Council on AIDS take responsibility for ensuring that matters relating to the widespread use of complementary therapies by people living with HIV/AIDS are adequately and appropriately examined and resolved.**

**Casemix**

Concerns were expressed during consultations and in submissions, especially from the community sector, about the impact of Casemix on the treatment and care of PLWHA. There is no intrinsic reason that Casemix should have a negative impact. The Casemix Branch of the Department of Human Services and Health reports that HIV is fully and adequately covered within the Australian National Diagnosis Related Groups (AN-DRGs) classification and that any downgrading of services is not due to the application of the classification but rather to budget cuts by the States and Territories. There are currently five different AN-DRGs (AN-DRG Version 3) that cover a range of HIV/AIDS diagnoses; each group receives a separate cost weight. Assignment to the HIV group depends on a principal diagnosis of HIV infection (ICD-9-CM code 042) or a principal diagnosis of an HIV-related complication together with a secondary diagnosis of HIV infection.

There is, however, a need for Casemix payment systems to deal with the question of community care. As Casemix evolves and is implemented, protocols of extended AN-DRGs (that is, for a total 'package' of care that includes hospital stay and home and community care) should be introduced. Currently, Casemix Branch is developing a Developmental Ambulatory Classification System to accommodate the care needs of outpatients.

Consultative mechanisms are available in the form of the Immunology and Infectious Diseases Clinical Coding and Classification Group, which provides advice and recommendations to the Australian Casemix Clinical Committee. This Group is due to finalise its recommendations by December 1995, in preparation for the next version of AN-DRG, due for release in December 1997.

As additional Casemix classifications are developed and refined, it will be possible to include in the Casemix payment system requirements for meeting certain minimum standards of care.

**Recommendation 32**

**It is recommended that the Commonwealth develop, as a matter of urgency, Casemix payment systems that include care in the community and that require minimum standards of care to be met.**

### **Infection control guidelines**

During the second Strategy considerable effort has been devoted to the development of infection control guidelines. A review of the guidelines was initiated early in 1994 in response to concern about possible HIV transmission in surgical and dental practice. The concern followed the documented transmission of HIV in a dental practice in Florida and the release of a report of apparent patient-to-patient transmission of HIV during minor surgery in a private practice in Sydney. The review was carried out by a joint working party of ANCA and the National Health and Medical Research Council, which produced a report entitled *Infection Control in Office Practice: medical, dental, and allied health*. This was endorsed by ANCA in June 1994 and widely distributed (approximately 7500 copies). The joint working party is involved in a range of activities to promote implementation of infection control guidelines. There has been extensive community consultation and a wide range of professional bodies have been involved.

### **Tuberculosis and HIV**

The second Strategy highlighted tuberculosis as a treatment area requiring careful monitoring because HIV infection may reactivate TB in people with previously inactive TB and may speed HIV-positive people's progress to AIDS. HIV-positive people are also more susceptible to becoming infected with TB because their immune system is weakened. There is a global resurgence of TB and an emergence of strains that are resistant to many drugs; this could affect PLWHA in Australia.

Between 1987 and 1993, the last year for which data are available, Australia had a stable annual incidence rate of TB, with between five and six notified cases per 100 000 population. This is low, even when compared with other developed countries (Hargreaves 1995). But the rates are not uniform across the community; they are significantly higher among Aboriginal and Torres Strait Islander people and people born in countries with a high prevalence of TB. Multi-drug-resistant TB has not become a significant problem for people with HIV (Curran & Dawson 1995).

From the limited data available it has been estimated that about 2–3 per cent of people with AIDS in Australia also have TB, and about 2 per cent of TB cases occur in people with HIV infection. These figures suggest that co-infection does not yet affect a large number of PLWHA.

State and Territory health authorities have responsibility for TB control within their jurisdictions. Several States, including those with the largest number of PLWHA, have revised their TB control guidelines during the second Strategy.

In November 1993 the National Health and Medical Research Council endorsed the document *Towards Elimination of Tuberculosis*, which established a strategic framework for the control of TB in Australia. Since

December 1993 the Council's Tuberculosis Working Party has been developing detailed protocols and guidelines, as recommended in the 1993 document, and these are expected to be available for public consultation by the end of 1995. PLWHA and Aboriginal and Torres Strait Islander people have been identified as two community groups requiring particular consideration.

### **Recommendation 33**

**It is recommended that the Commonwealth Government and the Intergovernmental Committee on AIDS consider the report of the National Health and Medical Research Council's Tuberculosis Working Party as soon as it is available and implement its recommendations as appropriate. Tuberculosis monitoring and treatment should be incorporated in the Intergovernmental Committee on AIDS action plan to ensure medical preparedness for an epidemic of HIV/AIDS and tuberculosis among Aboriginal and Torres Strait Islander people. The Commonwealth should improve monitoring and surveillance of HIV/TB co-infection.**

#### **5.2.4 Implementation: has the model of care been successful?**

As noted, the Commonwealth is not prescriptive about how the States and Territories should spend funds provided under any of the three funding programs. It has worked with the members of the partnership to develop the principles and priorities identified in the Strategy but it leaves it to the States and Territories to plan and provide services in cooperation with the community sector. As a consequence, only a general picture of service delivery in relation to the model of care is possible.

#### **Quality of care**

Overall, the consultations and submissions to the evaluation evince a moderate degree of satisfaction with inpatient care. There are, however, reasonably consistent reports of problems with pain management for HIV-positive IDUs, poor-quality food and its lack of suitability for PLWHA, and the treatment of HIV-positive prisoners. There is also concern about variations in standards of care between hospitals around the country. NAPWA is of the view that the variation is too great and that more effort should be made to develop protocols to guide care in areas of low prevalence (Submission 69, p. 25).

The Commonwealth does not specify what quality control systems there should be for treatment and care projects or inpatient care. State and Territory governments report a variety of quality control mechanisms, ranging from performance indicator systems to surveys of client satisfaction and encouraging the use of health complaints tribunals.

**Recommendation 34**

**It is recommended that Australian National Council on AIDS commission the Clinical Trials and Treatments Advisory Committee to review the current stage of development of clinical protocols in HIV/AIDS medicine, to report on those areas where the development of protocols is feasible and worth pursuing, and to propose a method of implementation.**

**Accessibility**

A consistent picture of good access in metropolitan areas counterbalanced by poor access in many rural and remote areas has emerged from both consumers and service providers. Problems with access are discussed in Section 5.2.2 in relation to GP services, dental health, intermediate care, volunteer care, pharmaceuticals and mental health.

The groups reported to be most likely to have increased difficulty gaining access to services are Aboriginal and Torres Strait Islander people, IDUs, prisoners, people of non-English-speaking background, women, people of trans-gender orientation, young people, and homeless people.

Some of the successes in improving access to services identified during the consultations were palliative care (although the improvements are not consistent), the expansion of sexual health services and the provision of HIV ambulatory care through these services, improvements in facilities in some hospital AIDS wards, the provision of high-technology treatments in home settings, and the commencement of some community-based drug trials in smaller States.

**Timeliness of care**

The timeliness of inpatient treatment is determined by the availability of hospital beds. The Hospital Funding Grants are a contribution to the cost of treating people with AIDS, not a guarantee that every person living with HIV/AIDS and requiring hospitalisation will receive it immediately. On the whole, the situation with the timeliness of inpatient care is quite positive. Consultations and submissions revealed periodic problems in the Australian Capital Territory, New South Wales (Sydney) and South Australia. These appear to relate mainly to peaks in demand. In South Australia and the Australian Capital Territory, however, there have been continuing discussions about whether there should be AIDS-specific wards in Royal Adelaide and Woden Valley Hospitals.

In the case of community care, there are consistent reports of delays with highly specialised drugs in most States and Territories. This is sometimes attributed to delays in the funding process (New South Wales) and sometimes to the time taken to bring the drugs in (the Northern Territory). The previously mentioned problem with availability of volunteers has led to delays in

## DYING AT HOME

*'I was sitting with him reading the paper. We'd been talking. I left the room only for a few minutes to start preparing dinner and when I went back in he'd gone.'*

—Michael

Michael is one of the hundreds of Australians who have chosen to look after a person in end-stage AIDS wishing to die at home.

Many people with AIDS want to die at home and there is nothing new about this—until recently most people died in their own homes according to HIV/AIDS author, Phil Nott, whose manual, *Dying At Home* is in its third reprint.

'Deciding on this option is one thing, enlisting the support of carers is another and after being involved in a carers' team, looking after a friend with AIDS, I realised what a huge commitment this was,' Phil said.

'After our experience I decided to write *Dying at Home* to help people with AIDS to decide whether dying at home could be a possibility for them and to pass on to other carers what we had learnt from our time supporting John.

'John's death at home happened smoothly. Maybe we were lucky. I suspect this was not the case. Planning and having supports in place contributed a great deal,' Phil said.

'*Dying at Home* spells out the areas John and his primary carer addressed. It also incorporates a number of suggestions from the people I interviewed. These included many workers in the field and the carers of 16 people who died at home from AIDS.

'These people acquired the virus in a variety of ways and at different ages. In spite of these differences, there was an extraordinary similarity in the experiences and concerns of their carers.'

Phil became interested in the role of carers when he and his partner organised a network of community and professional support to help John die in his own home.

'After John's death I questioned why so many people died in hospital when, with planning and supports in place, dying at home could be a real possibility,' he said.

With a grant from the National AIDS Campaign, Phil wrote the manual, which addresses more than 40 issues, from the need for laughter and retaining a sense of humour to planning your funeral. There is even a section on the option of euthanasia.

Phil acknowledges that dying at home is not for everyone and being a hands-on carer is also not for everyone.

'But one of the most important benefits is that you are not excluded from any part of the living/dying experience,' he said. 'We were with John when he was alive, when he died and afterwards. We laid him out, put him in his coffin and went with him to the funeral service. At no stage was he taken away from us.'

receiving volunteer services in Victoria. Mental health and counselling services are also reported to be subject to delays in several States and Territories.

### Conclusions

Do PLWHA receive high-quality, accessible and timely services that are based on a continuum of care and delivered in a way that is empowering? The answer varies according to the type of service you need, where you live, and the population sub-group to which you belong.

If you live in a large metropolitan area, you have a reasonable chance of a continuum of care of reasonable quality. Problems begin once you move away from the city or if you belong to a marginalised group: access to high-quality, confidential pre- and post-HIV test counselling will be more difficult; access to a GP competent in HIV medicine and with Highly Specialised Drug Scheme prescribing accreditation will be more difficult, if not impossible; access to a hospital pharmacy will be more difficult; and access to community support, and especially to volunteer community care teams, will be more difficult, maybe impossible.

It could be argued that this is simply a reflection of the health system as a whole, combined with the reality of where the epidemic is most prevalent and the highly specialised form of care required, especially in the care of people with AIDS.

The question is, is access to quality care more problematic for PLWHA than it needs to be, given that providing specialised care outside metropolitan areas and to marginalised groups is a systemic problem that cannot be remedied by improvements in HIV/AIDS treatment alone? The States and Territories need to ask themselves this as they prepare treatment and care plans at a State and Territory and regional levels. It also needs to be asked by the Commonwealth in the areas in which it has responsibility.

The generally positive picture of service delivery for PLWHA in metropolitan areas is no cause for complacency. There is room for much improvement in many aspects of delivery, among them boosting access to quality GP services, dealing imaginatively with the problem of AIDS-related dementia, preparing for an increase in AIDS among Aboriginal and Torres Strait Islander people, ensuring the viability of volunteer services in affected communities, developing better health maintenance and monitoring services, and catering for the needs of HIV-positive women.

This 'wish list' raises the question of the adequacy of planning and priority setting at the Commonwealth and State and Territory levels. Planning processes that allow for the monitoring of trends in the distribution of the epidemic and its changing clinical manifestations and for reviewing the adequacy of existing services are obviously desirable, as are transparent ways of dealing with multiple competing demands. It is reasonable that, as part of the process of monitoring the implementation of the Strategy, the Commonwealth should

require State and Territory governments to have developed comprehensive treatment and care plans as a condition for the receipt of funding.

### **Recommendation 35**

**It is recommended that, as part of the process of monitoring the implementation of a third National HIV/AIDS Strategy, the Commonwealth require State and Territory governments to have developed comprehensive treatment and care plans based on the concept of a continuum of care as a condition for the receipt of funding.**

The analysis of the balance between community care (both government and non-government) and inpatient care shows a large bias in favour of inpatient care. There is something of a vicious circle here: inadequate community care services increase the demand for inpatient services, leaving fewer funds available for community care. In reality, though, the funding for inpatient and ambulatory care comes from different funding programs. Transfer of funds between the Matched Funding Program or the Special Funding Program and the Medicare Hospital Funding Grants is, in theory, not possible. Although this provides some protection for non-inpatient funds, it creates considerable rigidity in the ability to plan across the continuum of care and allocate funds to areas of need in the community. This is discussed in Section 5.4.

It is not the Commonwealth's role to be involved in planning health service delivery at the 'micro' level. But, if it is to continue to provide considerable funds to State and Territory governments for treatment and care services, the foregoing analysis suggests there is an urgent need to develop performance indicators.

In the case of the Hospital Funding Grants, the States and Territories are not required to submit plans or report on service delivery. This is an unsatisfactory situation for the Commonwealth because these Grants constitute the major component of HIV/AIDS funding to the States and Territories yet the Commonwealth can neither direct how the funds will be used nor report in a sound and reliable way on what has been achieved with the funds. This is also discussed in Section 5.4.

## **5.3 THE OUTCOMES OF THE TREATMENT AND CARE PROGRAM**

Chapter 2 presents data on changes in HIV/AIDS survival rates and changes in the clinical manifestations of HIV/AIDS that might be attributed to developments in treatment and management. Some of these changes may translate into enhanced quality of life but others may not. At the PLWHA consultation workshop conducted for the evaluation in Sydney, it was made clear that increased survival time does not necessarily mean enhanced quality of life.

Some promising results, based predominantly on virological and

immunological markers, have emerged from treatment strategies employing combination antiretroviral therapy, newer agents such as protease inhibitors and lamivudine (3TC), and therapy in earlier stages of HIV disease. Further evaluation will be required to determine whether these regimens have greater clinical efficacy and produce more significant survival benefits than existing antiretroviral therapy. Advocacy of early combination antiretroviral therapy makes biological sense in light of probable synergistic or additive effects of therapy and delayed emergence of viral resistance. There is, however, increasing realisation that this approach requires prolonged treatment with multiple potent agents during the early stages of HIV infection, when people are essentially well.

It is not possible to calculate in any meaningful way whether or not overall quality of life for PLWHA has improved and determine what role the Treatment and Care Program has had in this. In absolute terms, HIV/AIDS remains an incurable, chronic, debilitating disease. Nevertheless, the areas of success that are noted in this report should not be undervalued. There are still significant gains to be made in the management of HIV/AIDS and these revolve around ensuring that the model of care envisaged in the Strategy is more fully realised.

### 5.3.1 The efficiency of the Treatment and Care Program

#### Routinely collected health service usage data

For this report, the most recent Australian Institute of Health and Welfare data on admissions to public hospitals were for 1991–92 (Hurley 1995). Table 5.7 summarises the rates of HIV-related admissions for care in each State and Territory for 1991–92. There were 11.3 admissions and 44.4 bed-days per person living with AIDS in Australia. There was considerable variation

**Table 5.7 Numbers and rates of HIV-related hospital admissions and bed-days, by State and Territory, 1991–92**

State/Territory	No. of PLWA <sup>a</sup>	No. of admissions	No. of bed-days	Admissions per PLWA	Bed-days per PLWA
NSW	726	8 566	33 246	11.8	45.8
Vic	270	4 697	17 138	17.4	63.5
Qld	112	567	3 236	5.1	28.8
WA	62	204	234	3.3	3.8
SA	66	113	1 612	1.7	24.4
Tas	6	13	96	2.2	16
ACT	14	55	422	39	30.1
Total	1 256	14 215	55 984	11.3	44.4

a. As at December 1991.

Notes: Hospital admissions with ICD9-CM codes 042, 043 or 044 as the primary or secondary diagnosis.

Data were not provided for the Northern Territory.

Source: Hurley (1995).

between States and Territories in these two indicators of hospital utilisation—the admission rate was about 47 per cent higher in Victoria than in New South Wales, and the bed-day rate was about 38 per cent higher. The number of admissions was quite small for all States and Territories except New South Wales and Victoria.

In 1992–93 two drugs for the management of HIV infection were available under the Highly Specialised Drugs Scheme—the antiretroviral agents zidovudine and didanosine. Table 5.8 summarises details of their use in New South Wales and Victoria. The rate of use of both drugs was higher in Victoria: 27 per cent higher for zidovudine and 50 per cent higher for didanosine. The combined cost per person-year for the two drugs was \$1476 in New South Wales and \$1927 in Victoria.

**Table 5.8 Use rates of zidovudine and didanosine, New South Wales and Victoria, 1992–93**

State	No. of person-years	Use rate (g/person-year)	
		Zidovudine	Didanosine
NSW	4 290	49.5	10.5
Vic	1 710	63.0	15.4

Note: Person-years for patients with either CD4+ count <500 x 10<sup>9</sup>/l or AIDS: estimated by NCHECR.  
Source: Hurley (1995).

### The cost of treatment and care for people with HIV infection

The two most recent Australian studies of the cost of treatment and care for adults with HIV infection were conducted by Hurley et al. (1995a, 1995b). The first was a prospective survey conducted in Victoria in 1992–93 of hospital- and community-based care received by 128 homosexual men (1995a). Patients in four phases of HIV infection were surveyed and the study included a random sample of around 20 per cent of people living with AIDS in Victoria at that time. The survey showed that health service use by men in the early phases of infection was around five times higher than that of Australian men of the same age (1995c). As would be expected, health service use increased and became more hospital based as HIV illness progressed. Average monthly health care costs increased from \$331 in phase 1 to \$677 in phase 2, \$1372 in phase 3, and \$7099 during phase 4 (AIDS). In the early phases of infection, drugs constituted around 50 per cent of monthly costs; the figure decreased to around 30 per cent of costs for patients with AIDS. In contrast, hospital admissions were rare in phases 1 and 2, but bed-day costs constituted 60 per cent of costs after diagnosis of AIDS.

In the second study Hurley et al. (1995b) estimated the present value of the lifetime cost of HIV infection, including AIDS. They noted that health care costs for patients with AIDS were substantially higher in the last few months

of life, with monthly costs averaging \$4000–\$5000 until three months before death, then increasing to almost \$16 000 in the last month of life. The average present value of the lifetime cost for men diagnosed when their CD4+ lymphocyte count dropped below 500 x 10<sup>6</sup>/l (the median time of diagnosis) was \$93 000 (1992–93 prices).

### The national costs of HIV infection

Hurley et al. (1995d) estimated the cost of treatment and care for HIV infection in Australia in 1992–93 at \$130 million. The Commonwealth was estimated to have provided 62 per cent (\$80 million), the States and Territories 35 per cent (\$46 million), and patients and their families 3 per cent (\$4 million). Table 5.9 summarises components of this estimate.

The indirect costs associated with loss of earnings due to hospitalisation for HIV/AIDS-related treatment were estimated to be \$42 million. Indirect costs due to earnings forgone through premature death caused by HIV/AIDS were found to be \$271 million. The total indirect cost of HIV/AIDS in Australia in 1992–93 was therefore estimated to be \$313 million.

There have been few studies of the cost of HIV infection in Australia. They are needed for assessing the cost-effectiveness of HIV prevention programs. The monthly service use and cost data also provide a useful description of patterns of care and could be used to identify aspects of treatment and care that are sub-optimal in terms of cost-effectiveness. For example, treatment costs were very high in the last few months of life: alternative models of care might provide

**Table 5.9 Estimated cost of treatment and care for HIV infection in Australia, 1992–93**

(\$million)	
Type of cost	Cost
Direct costs	
Ambulatory care <sup>a</sup>	17.0
Hospital bed-days <sup>b</sup>	42.8
Investigations and procedures	11.3
Drugs	54.6
Miscellaneous <sup>c</sup>	4.3
<b>Total</b>	<b>130.0</b>
Indirect costs	
Morbidity	42.3
Mortality	271.1
<b>Total</b>	<b>313.4</b>

a. Includes outpatient and community-based medical and allied health practitioner consultations.

b. For 'hotel' costs, medical and nursing care: excludes drugs and investigations.

c. Home-based and community organisation services, travel and health services.

Notes: Components do not necessarily sum to total due to rounding.

Source: Hurley et al. (1995d).

equivalent quality of life at less cost. A regular national survey of service usage and costs is required to inform this assessment. Such a survey would be in keeping with the ‘challenge’ identified in the second Strategy to develop ‘... the methodologies and systems to monitor service utilisation by people with HIV/AIDS and its costs’ (Commonwealth of Australia 1993a, p. 27).

### Recommendation 36

**It is recommended that the Intergovernmental Committee on AIDS introduce a national survey of service use and costs in the treatment of people living with HIV/AIDS, combined with measures of the quality of life for patients.**



### The efficiency of treatment and care

The notion that treatment for patients with HIV infection should represent an efficient use of available resources is embodied in the objective of the Treatment and Care Program. Assessing whether the Program is improving quality of life in a cost-effective manner is a challenging task (Hurley & Butler, 1995b). There have been no Australian studies of the cost-effectiveness of treatment and care regimens for HIV/AIDS, and only very limited data on the actual treatment regimens used are available. It was not possible to conduct either cost-effectiveness studies or surveys of treatment patterns in the time available for this evaluation.

Appraising the overall efficiency of the Treatment and Care Program for HIV/AIDS in Australia is difficult for at least two reasons. First, an alternative scenario against which the present Treatment and Care Program can be compared must be specified. Second, the overall Treatment and Care Program encompasses a number of health care interventions and the cost-effectiveness of each of these interventions may vary widely.

Bearing these difficulties in mind, there are three approaches that can be adopted to obtain an indication of the cost-effectiveness of the overall Treatment and Care Program for HIV/AIDS in Australia; taken together, they would provide guidance about the bounds within which the cost-effectiveness of the overall program is likely to fall.

#### *First estimate*

The first approach is based on the lifetime treatment cost of a person with HIV infection, and assumes that the alternative to the present Treatment and Care Program is no treatment and care; that is, the effectiveness of the present program is compared against the natural history of HIV/AIDS. As stated, the estimated lifetime cost of treatment and care of a male with HIV infection in Australia in 1992–93 was \$93 000. The effectiveness of this treatment is taken to be the difference between the mean survival time from diagnosis of AIDS to death in early cohorts of AIDS patients (nine months—Bindels et al. 1991) and the corresponding mean survival time from diagnosis of AIDS cases in Australia today (18 months—calculation by the National Centre in HIV Epidemiology and Clinical Research unpublished) or an increase in survival of nine months. This gives an estimated cost per life-year saved of \$124 000.

It is possible that the mean survival time of nine months in the early cohorts of AIDS patients reflects the effects of some basic treatments available at that time, in which case treatment and care may be increasing survival by more than nine months in comparison with the natural history scenario. It is, however, quite unlikely that the increase in survival would have been more than 24 months. If an additional two years of survival is attributed to the Treatment and Care Program at a cost of \$93 000, the cost per life-year saved would be \$46 500.

These increases in survival times assume that the extra months of life are lived in full health. If this is not so, then a quality-of-life weight of less than 1 should be used to convert the increase in survival to quality-adjusted life-years saved. Taking a quality-of-life weight of 0.5 and an increase in survival of nine months suggests a cost per quality-adjusted life-year saved of \$248 000.

#### *Second estimate*

A second approach to investigating the efficiency of the Treatment and Care Program, also using the natural history of HIV infection as the baseline, is to consider the number of people living with AIDS in 1992–93 and who would

therefore have been beneficiaries of the treatment and care expenditures of \$130 million in that year (Butler 1995b). The number of people living with AIDS in Australia at the end of 1992 was 1315 and at the end of 1993 it was 1365 (data from the National Centre in HIV Epidemiology and Clinical Research). Taking the simple average of these (1340) provides an estimate of the number of people living with AIDS for the financial year 1992–93. If each of these people gained an additional two years of life in full health as a result of the Treatment and Care Program, the cost per life-year saved would be \$48 500. If, however, one additional year of life is taken as the estimate of increased survival and a quality-of-life weight of 0.5 is assigned to that year, the cost per life-year saved is \$194 000.

#### *Third estimate*

A third approach to investigating the efficiency of the Treatment and Care Program is to estimate the incremental costs and effectiveness of treatment and care in 1992–93 compared with treatment and care at an earlier time in Australia (Hurley & Butler 1995b). Using data from Whyte (1987), the cost of treatment of an AIDS case in 1986 in Australia was about \$32 000 (in 1992–93 prices) and the mean survival time from diagnosis to death was about seven months. If the mean survival time from diagnosis to death in 1992–93 is taken as 18 months and the lifetime treatment cost of an HIV-infected person in that year was \$93 000 the incremental treatment cost in 1992–93 over 1986 is \$61 000, the incremental survival is 11 months, and the incremental cost per life-year saved is \$67 000. If a quality-of-life weight of 0.5 is attached to the increased survival, the cost per life-year saved is \$134 000.

#### *Conclusion*

The three alternative approaches adopted in this analysis suggest that the cost per quality-adjusted life-year saved in this Program, in comparison with the natural history of the disease, probably lies in the range \$45 000 to \$248 000. In comparison with the costs and effectiveness of treatment and care in Australia in 1986, the cost per quality-adjusted life-year saved probably lies in the range \$65 000 to \$135 000.

These estimates represent the average efficiency of a number of quite different treatment regimens, and the efficiency of each regimen could vary markedly from the average. The two most notable changes in treatment practice between 1986 and 1992 have been the use of prophylaxis for PCP and antiretroviral drug therapy. Based on the published cost-effectiveness literature, it seems likely that prophylaxis of PCP with cotrimoxazole or dapsone is considerably more efficient than this average, with a cost per year of life saved of around \$13 000. In contrast, the published cost-effectiveness literature on antiretroviral therapy suggests it may be considerably less efficient than the average.

To determine whether the Treatment and Care Program is meeting its objective, a continuing, prospective evaluation process would need to be established. It would need to include systems for the following: assessing the effectiveness, the impact on quality of life, the costs, and the cost-effectiveness of alternative treatment regimens for the many manifestations of HIV infection; monitoring current treatment practices; and disseminating the results of these assessments and the monitoring process to health care providers, patients and policy makers in order to inform decisions about treatment and care at both an individual and a policy level.

## **5.4 THE APPROPRIATENESS OF THE TREATMENT AND CARE PROGRAM**

### **5.4.1 The pace and direction of mainstreaming**

The second Strategy says that strategic planning for mainstreaming of HIV/AIDS programs and activities should occur between 1993–94 and 1995–96.

One element of mainstreaming that has occurred at the Commonwealth and State and Territory levels is the integration of HIV/AIDS administration with larger public health entities. For example, at the Commonwealth level the AIDS/Communicable Diseases Branch of the Department of Human Services and Health now administers the various HIV/AIDS programs as well as the Commonwealth's policies and programs relevant to communicable diseases. A similar realignment has happened in New South Wales with the creation of the AIDS/Infectious Diseases Branch and in all other States and Territories. There is no particular pattern in how these mergers and amalgamations have taken place, but, considering the diversity of State and Territory health service infrastructure, it is difficult to see them as having happened in anything but an incremental way.

At the level of service delivery, State and Territory governments report a range of examples of mainstreaming. Smaller States and the Territories say they have always worked on a mainstream model because of the low prevalence of HIV/AIDS.

During the consultations that were part of the evaluation process a number of successful and unsuccessful examples of mainstreaming were identified. Lack of success was associated with a lack of commitment to the provision of HIV/AIDS services or an inability to properly provide these services because of the pressure of other demands. A number of principles that could be used to guide successful mainstreaming were identified:

- a proper assessment of the capability of mainstream services to take on an HIV/AIDS role on a service-by-service basis;
- commitment on the part of the mainstream service to providing for the needs of PLWHA;
- support for mainstream agencies from HIV/AIDS specialist services;

- good case management involving specialist and mainstream services;
- provisions for accountability in relation to funding and care quality;
- the existence of reasonable complaints and advocacy mechanisms.

On the whole, it is possible to say that mainstreaming is no longer the feared enemy of quality HIV/AIDS service provision it once was. There is wide acceptance of the need for both specialist and generalist services as part of the continuum of care. If it is desirable to move towards maximising mainstream service provision, then a third Strategy should introduce goals or targets to encourage this in a strategic and well-planned way. Integral to this process is the continuing priority of educating and training health care workers.

#### **Recommendation 37**

**It is recommended that the Intergovernmental Committee on AIDS and the Australian National Council on AIDS agree on a set of principles that can be used to guide mainstreaming of HIV/AIDS treatment and care activities during the course of a third National HIV/AIDS Strategy. They should also agree on a set of outcome measures that can be used to monitor performance in this regard.**

### **5.4.2 Broadbanding of Commonwealth funding**

The second Strategy states,

During the term of the ... Strategy, the Commonwealth and the States/Territories will undertake consultation and planning through the IGCA to determine the ways in which HIV/AIDS programs can best be included in broad funding programs for health services, with inbuilt accountability mechanisms. (Commonwealth of Australia 1993a, p. 45)

Now that the number of cases of AIDS has peaked (at least for the time being) and the methods of responding to HIV/AIDS have become relatively stable and predictable, State and Territory governments should be required to plan for and respond to HIV/AIDS in the way they are required to plan for and respond to other diseases. The current arrangement is unsatisfactory for the Commonwealth because of the problems with accountability and performance monitoring, especially in relation to the Medicare Hospital Funding Grants for AIDS.

The major obstacle to broadbanding treatment and care funds is the great disparity in the way the epidemic is distributed. As Chapter 2 shows, by far the greatest impact of the epidemic is in New South Wales.

The three sources of funds for the Treatment and Care Program that need to be considered in this discussion are the Medicare Hospital Funding Grants for AIDS, the Matched Funding Program, and the Special Funding Program. There are three options available to the Commonwealth:

- A maintain all three funding programs but build in performance measures for the Medicare Hospital Funding Grants for AIDS component;
- B maintain the Matched Funding Program and Special Funding Program but incorporate the Medicare Hospital Funding Grants for AIDS in general Medicare funds—this could occur at the time of renegotiating the Medicare agreements in 1998 or at the start of a third Strategy in 1996;
- C broadband the three funding programs into one program of funds to the States and Territories (removing the Medicare Hospital Funding Grants for AIDS from the Medicare agreements) and building measures of performance for the quantum of funds.

Options A and C have the advantage of distributing resources to where the epidemic is, and if the epidemic were to change in its distribution the funds would follow automatically. At present this compensates New South Wales for having the bulk of AIDS cases. On the other hand, a broader social equity argument says that HIV/AIDS should be treated like any other disease and these options continue to give HIV/AIDS special treatment.

Under option B the health system would be challenged to demonstrate the extent to which it has developed in response to HIV/AIDS. It can be argued that HIV disproportionately affects marginalised or stigmatised groups and that, because discriminatory attitudes are deeply embedded, PLWHA will be treated less well than other people in equivalent circumstances in the health system. But it is also true that the only way to deal with this problem in the long term is to keep up the training effort for health care workers and confront discrimination more generally through community education.

Options A and C leave within the hospital system identifiable AIDS funds that can help advocacy groups argue for the provision of services. Without identifiable funds advocacy may become more difficult. The absence of funds would have the positive effect of shifting the basis of advocacy from an argument about the proper use of earmarked AIDS funds to advocacy based on the rights of PLWHA as health care consumers.

Funds from the Matched Funding Program and Hospital Funding Grants are administered separately and, although the Strategy envisages an integrated continuum of care, the funding structure actually works against consolidated planning to achieve that aim. Only option C allows for the quantum of funds to be administered as a whole and for the Commonwealth to negotiate with the States and Territories across the continuum of care. Option A may allow some measure of negotiation across the continuum, but the aspect of the model of care most likely to be compromised in the absence of direct Commonwealth involvement is outpatient and community care, which is funded through the Matched Funding and Special Funding Programs. This is probably the area

where Commonwealth involvement in treatment and care adds most value; it should therefore be maintained in any scenario for a third Strategy.

Under option B there may be increased pressure on specialist HIV/AIDS service delivery in the face of a harsh fiscal environment at the State and Territory level. Commonwealth funds are, however, only a contribution to the total cost of treating a person with AIDS in hospital and the decision to set up specialist facilities is one that should be made on the basis of the need for such facilities in light of local service infrastructure and the local prevalence of HIV/AIDS. The absence of specially designated funds should not influence this decision-making process.

Option C offers an opportunity for the Commonwealth to use the full weight of its HIV/AIDS funding to the States and Territories to maximum advantage. It also offers the opportunity for the Commonwealth to redefine its purpose in the area of HIV/AIDS and clearly specify what results it wants from the States and Territories. This is predicated, however, on the ability of the Commonwealth to specify what it wants from these funds and to develop meaningful performance measures. Such an approach would also need to be based on serious concerns that current hospital services are not adequate and the belief that earmarked funds are the best way to resolve the situation. Although this evaluation notes some problems with access to care and variations in the standard of care, they are not problems that can be resolved only by earmarking funds.

Regardless of which option is chosen, for the reasons given in Section 5.2.2 the Commonwealth would want to maintain direct funding to the States and Territories for HIV testing and counselling services.

### **Recommendation 38**

**It is recommended that Treatment and Care Program funding for community-based service provision through the Matched Funding Program and the Special Funding Program be maintained in a third Strategy. Other avenues for recognising financially the uneven distribution of AIDS cases should be explored by the Commonwealth Department of Human Services and Health through the Commonwealth Grants Commission. When this has been resolved, the dedicated Medicare Hospital Funding Grants for AIDS should be incorporated in the general Medicare funding arrangements.**

# Maintaining the foundations— the Research Program

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## 6.1 THE RESEARCH PROGRAM

### 6.1.1 Objectives, principles and priorities

The objective of the Research Program of the National HIV/AIDS Strategy is to increase knowledge of ways to eliminate or limit the spread of HIV infection and to reduce the harm to individuals and the community resulting from HIV infection through supporting a comprehensive research program and ensuring research results are translated into practice. (Commonwealth of Australia 1993a, p. 29)

The Research Program has four guiding principles:

- Research should be undertaken within the health promotion framework provided by the Ottawa Charter.
- Priorities and resource allocation should concentrate on those aspects of research that are relevant to dealing with the epidemic and areas where the lack of research data is greatest.
- Research on the virus, its replication and pathogenesis should be directed toward providing essential information



that will facilitate the development of antiviral or immunomodulatory agents or vaccines.

- Priority should be given to social research that has a direct bearing on the management of the epidemic in the most affected communities, where the gay community is pre-eminent. (pp. 29–30)

The Research Program's priorities are to limit the spread of HIV infection, to reduce the harm to individuals and communities resulting from HIV infection, and to translate research into policy and practice. Under each of these priorities, the Strategy specifies general questions that cover the spectrum of virological, epidemiological, clinical and social research.

### **6.1.2 Scope and method of the assessment of the Research Program**

Because changes to the administration of the Research Program (resulting from the evaluation of the first Strategy) are still being implemented, this evaluation takes a limited approach to assessing the Research Program and focusses instead on the links between the Program and the rest of the Strategy.

The evaluation framework identified two key questions:

- What is the role of the Research Program in relation to the Strategy and is that role appropriate?
- Are the mechanisms linking the Research Program with the design and refinement of education and prevention and treatment and care programs effective and efficient in ensuring that the results of the Research Program are translated into practice and the research agenda is responsive to the problems posed by the HIV/AIDS epidemic?

### **6.1.3 Administrative and funding arrangements**

The Research Program provides funds for project grants, training awards, three National Centres (the National Centre in HIV Virology Research, the National Centre in HIV Epidemiology and Clinical Research, and the National Centre in HIV Social Research), the Community HIV/AIDS Research Network, the Clinical Trials and Treatments Advisory Committee, and the National HIV Reference Laboratory. The three National Centres constitute the core of the HIV/AIDS research effort and account for approximately 45 per cent of Research Program funds. Table 6.1 presents information on funding for 1993 to 1995.

The structure of the National Centre in HIV Social Research has changed during the second Strategy. In 1994 it was reviewed by a team led by Emeritus Professor Peter Karmel, which recommended the establishment of three National Priority Programs, focussing on men who have sex with men, people living with HIV/AIDS and the general population (with a special emphasis on young people). These Programs now liaise closely and are recognised as the

**Table 6.1 Funding for HIV research, by category of research, 1993 to 1995**  
(\$'000)

Research category	1993	1994	1995	Total	% of total funding
Project grants	3 184	3 145	3 060	9 389	24.9
Training awards	1 869	1 900	1 720	5 489	14.6
National Centre in HIV Virology	1 838	1 971	2 693	6 502	17.2
National Centre in HIV Social Research	1 220	1 073	1 474	3 767	10.0
National Centre in HIV Epidemiology and Clinical Research	1 973	2 305	2 491	6 769	18.0
Community HIV/AIDS Research Network <sup>a</sup>	265	383	390	1 038	2.8
Clinical Trials and Treatment and Advisory Committee <sup>a</sup>	176	482	490	1 148	3.0
National HIV Reference Laboratory <sup>b</sup>	1 258	1 184	1 254	3 615	9.6
Total	11 783	12 443	13 572	37 717	100.0

a. Community HIV/AIDS Research Network and Clinical Trials and Treatment and Advisory Committee are located within the National Centre in HIV Epidemiology and Clinical Research.

b. Based on estimates for annual expenditure extrapolated from financial year figures.

Source: Commonwealth of Australia (1995).

National Centre in HIV Social Research. An attempt to establish a Priority Program in Aboriginal and Torres Strait Islander social research did not come to fruition, but two Aboriginal and Torres Strait Islander research projects, one in central Australia focussing on traditional communities and one in Melbourne focussing on Aboriginal IDUs, are currently being developed.

Beginning in 1985–86, the majority of HIV/AIDS research has been funded under the supervision of the Commonwealth AIDS Research Grants (CARG) Committee, which was originally a committee of the AIDS Task Force. It became a sub-committee of ANCA in 1988 and remains so today. It has eight members: three social scientists, three from the biomedical and clinical areas, a community representative, and an epidemiologist. Its meetings are also attended by the directors of the National Centres in an ex officio capacity.

The second Strategy states that in the next two triennia planning would start for the gradual transfer of HIV/AIDS research to the National Health and Medical Research Council (NHMRC). In 1993 the CARG secretariat was transferred to the NHMRC administration in the Department of Human Services and Health.

In 1994 the three National Centres moved to a five-year funding cycle in keeping with national units of the NHMRC. The conditions of grant are comparable with those for the NHMRC units, except that the HIV National Centres' contracts continue to require them to remain responsible for informing HIV/AIDS policy development. It is proposed that the National Centres be reviewed in the penultimate year of their funding, as is standard NHMRC practice.

In 1995 selection of HIV/AIDS project grants and training awards (to start in 1996) was done through two NHMRC committees: the Medical Research Council and the Public Health Research and Development Committee. HIV/AIDS research was, however, protected by ‘ring-fencing’ the level of funds to be devoted to that purpose. During 1995, there are 57 current project grants, 28 of which are grants commencing in 1995. There are 55 current training awards (fellowships and scholarships), 24 of which are new awards for 1995. Table 6.2 shows the distribution of grants for 1995.

**Table 6.2 Grants distribution by research discipline, 1995**

Type of grant	Research discipline			Total
	Virology	Epidemiology/ clinical	Social and behavioural	
Project grants	14	5	9	28
Fellowships	5	1	–	6
Scholarships	7	3	8	18
Total	26	9	17	52

– Zero.

Source: Commonwealth of Australia (1995).

## 6.2 THE RESEARCH–PRACTICE RELATIONSHIP

The objective, principles and priorities of the Research Program make it clear that HIV/AIDS research should have a practical purpose. The link between research and practice is, however, neither straightforward nor without problems. The second Strategy does not allocate responsibility for ensuring that the research–practice relationship works effectively.

An examination of the different elements of the Research Program suggests that they should have different expectations placed on them in terms of linking with policy and practice.

### 6.2.1 Research with indirect links to practice

The CARG process has followed the NHMRC principles, which are based on the scientific merit of research proposals. Although policy relevance is considered, selection on the basis of merit means that there are limits to the extent to which research can be directed. The CARG secretariat reported to the evaluation on a special funding round of social research it initiated in 1991 into men who have sex with men to redress the perceived deficiency of policy-relevant research in this area. Twelve projects were funded. Some of them produced ‘incontestably valuable’ results, others were very slow in reporting their results, and others failed completely. The report suggested that one of the reasons for this was the liberal CARG award conditions, which do not require researchers to report their findings swiftly, comprehensively and effectively.

Another reason is the inadequate research expertise available to some of the projects. The CARG experience of attempting to direct research into policy-relevant areas through project grants shows that it can work but there must be tight administration and there may be trade-offs in terms of research quality. This experience should be noted within the NHMRC for the continuing management of the HIV/AIDS research grants if the goal of increasing the policy relevance of research is to be attained.

The training awards program is intended to develop in Australia a core of HIV expertise rather than produce useable ‘results’. It may be possible to judge the cumulative effect of such a program after a number of years.

Although breakthroughs in understanding HIV/AIDS from a virological or immunological perspective may lead to profound changes in public health policy, this type of research is not expected to produce useable results for policy and practice on a project-by-project basis. Traditional academic methods of producing and evaluating the output of biomedical research are therefore appropriate and the links between the National Centre in HIV Virology Research and policy are satisfactory.

The objective of the Research Program is unrealistic in its implied expectation that all research will be translatable into practice.

#### **Recommendation 39**

**It is recommended that in a third National HIV/AIDS Strategy the Commonwealth alter the objective of the Research Program to say that research results should be translated into practice where appropriate.**

### **6.2.2 Research with more direct links to practice**

The National Centre in HIV Epidemiology and Clinical Research and the National Centre in HIV Social Research have been funded by the Commonwealth with the deliberate purpose of ensuring a close link between research and practice.

This evaluation of the second Strategy is a prime example of the interaction between social and behavioural research, epidemiology and policy making. Epidemiological and social and behavioural research data are central to measuring the effectiveness of the Education and Prevention and the Treatment and Care Programs. Members of the National Centre in HIV Epidemiology and Clinical Research and the National Priority Program for Men who Have Sex with Men advised the evaluation and provided data important to the evaluation, as did the National Priority Program for the General Community. It is essential that this link between policy and research be developed and fostered as the need to monitor the Strategy outcomes moves into a new phase in a third Strategy.

A matter requiring further consideration is the question of where the responsibility lies for evaluation research and for HIV/AIDS surveillance and related epidemiological research. HIV/AIDS surveillance is currently located within the National Centre in HIV Epidemiology and Clinical Research. Although it is currently funded out of the Research Program, it is not strictly research and it has a vital public health function. There is also the larger question of the most appropriate funding and administrative arrangements for communicable diseases surveillance and epidemiological research more generally. The current arrangements for HIV/AIDS surveillance are working well, so it is appropriate that they continue and be considered as part of the 1997 review of the National Centres. Funding for large social surveys research to monitor social and behavioural factors related to the transmission of HIV has come from the national evaluation budget. Effective implementation of the research results in the long term will require close collaboration between the Department of Human Services and Health and the National Centre in HIV Social Research. It should also be considered as part of the review of the National Centre in HIV Social Research in 1997.

The support of clinical trials through the Clinical Trials and Treatments Advisory Committee and the Community HIV/AIDS Research Network demonstrates a linking of research and practice to the point where the two are inseparable. As discussed in Section 5.2.2, clinical trials have the dual function of providing access to the latest therapies and providing research data on the effectiveness of those therapies. A large number of HIV clinicians participate in the Australian arm of international clinical trials and are therefore involved in both the production and use of research. Given that Australia has a relatively small number of people living with HIV/AIDS, the number of clinical trials that include an Australian arm is an indicator of the success of the Clinical Trials and Treatments Advisory Committee and the Community HIV/AIDS Research Network in facilitating clinical trial research in Australia.

The Sydney Men and Sexual Health study involves collaborative research by two National Centres (the Macquarie University National Priority Program for Men who Have Sex with Men and the National Centre in HIV Epidemiology and Clinical Research) and the AIDS Council of New South Wales. It also involves over 250 general practitioners and over 1000 gay men. The study is well recognised for its capacity to inform policy and practice in Sydney, which remains the epicentre of the HIV epidemic in New South Wales and Australia.

There are numerous other examples of research and practice being linked both formally and informally:

- The chairperson of the ANCA education sub-committee is the director of the National Priority Program on the General Community and other members of the sub-committee are representatives of State and Territory governments and community sector organisations.

- The New South Wales AIDS/Infectious Diseases Branch established a ‘Policy Analyst—Prevention’ position in early 1995, with the task of bringing together research of relevance to HIV health promotion and ensuring that it is accessible to workers in the field.
- The National Centre in HIV Social Research provides regular reports through the National AIDS Bulletin, describing the research efforts of the Priority Programs.
- The National Centre in HIV Social Research has hosted an annual two-day conference in each of the last three years, focussing on the theme ‘from theory to practice’. These conferences bring together researchers, people living with HIV/AIDS, health practitioners, and public servants and foster interaction around the conference theme.

There is another dimension of the research–practice relationship that is evident to some extent in the Clinical Trials and Treatments Advisory Committee and the Community HIV/AIDS Research Network and where social researchers are involved with educators in developing and evaluating new approaches to health promotion. This might be described as ‘applied health services research’, where critical questions about the effectiveness of public health interventions are placed on the research agenda. The use of epidemiological and social research in this evaluation might be seen as a ‘macro’-level example of this relationship. An area where this could be explored more fully at the ‘micro’ level is the development, implementation and evaluation of services for Aboriginal or Torres Strait Islander communities.

There are, however, areas where the research–practice relationship is frustrated. Several submissions to the evaluation expressed concern that the results of research are not provided quickly enough or in a form that is appropriate for the network of organisations that might be interested in them. This concern is particularly relevant to people who live outside the south-eastern corner of mainland Australia.

### **6.2.3 The contribution of Australian research**

The following contributions of Australian research have been identified :

- the development of the concept of ‘negotiated safety’, which informs our understanding of sexual practice among gay couples, and the development and measurement of ‘gay community attachment’ as an understanding of the social distance between homosexually active men and the gay community;
- cohort studies of homosexually active men that have enhanced understanding of the social and psychological aspects of the prevention of AIDS and assisted the development of education campaigns;
- the development of research methods for use with previously unstudied or understudied populations such as homeless youth, homosexually active men,

## AUSTRALIAN MEDICAL RESEARCH WORLD CLASS

Professor John Mills, director of the National Centre in HIV Virology Research (NCHVR) was living in San Francisco during the 1980s, in the thick of the United States' AIDS epidemic.

In 1985 he was invited to Australia to lecture in east coast capital cities about the US experience with HIV infection and AIDS and, after several subsequent visits, including a sabbatical leave at the Walter and Eliza Hall Institute in 1991, he was recruited to Australia in 1992 to become director of the Macfarlane Burnet Centre for Medical Research and simultaneously director of the NCHVR. The NCHVR was established in 1987 to lead Australia's fundamental research into HIV infection. The Centre consists of laboratories in Brisbane, Sydney, Canberra, Melbourne and Adelaide and scientists within the Centre collaborate with HIV researchers throughout Australia. Four of the eight NCHVR laboratories are located at the Macfarlane Burnet Centre in Melbourne.

'At the National Virology Centre we are now involved in almost every aspect of research into HIV,' he said. 'This includes fundamental studies of how the virus replicates, studies of how HIV infection produces disease and how the immune system fights this infection. We are developing new treatments for HIV infection and have done important work on how the virus becomes resistant to current treatments such as AZT. Recently, we have also become involved in the search for a vaccine to prevent HIV infection.'

The National Centre has about 50 staff working in the eight laboratories. 'Although the majority of the Centre's funding comes from the Commonwealth Government, through the Department of Human Services and Health, funding for some HIV research projects in these laboratories comes from private donations and the pharmaceutical industry,' John explained.

He admitted the NCHVR research team is constantly frustrated by the lack of progress in finding a cure or an effective treatment for this infection. 'Scientists generally tolerate frustration pretty well,' he said, 'but it is dispiriting not to be able to offer patients anything better than the drugs we have now. This virus has turned out to be a more difficult problem to solve than any of us would have imagined 10 years ago, when it was discovered.'

John made the point, however, that Australia's contribution to HIV research has been remarkable, especially considering the funding available and the small number of people working on the problem here. 'There are certainly political leaders in Australia who feel that it is futile for a country as small as ours to be doing AIDS research, since so much work is being done overseas in Europe and the US,' he said. 'That's nonsense as there is tremendous scientific talent here and the past record shows that Australians can make discoveries, even Nobel-prize-winning discoveries, which contribute dramatically to bettering human health.'

NCHVR investigators recently developed a new drug for treatment for HIV infection which will soon be tested on humans. But John Mills pointed out that the drug will not be available on prescription for at least several years. 'The reality is that new drug discovery and the clinical trials necessary to show that new drugs are safe and effective take a long time.'

He is, however, optimistic about the future of HIV research. 'There are already four drugs available that can slow the progression of HIV infection to some extent and by the year 2000 we'll probably have at least another four drugs and perhaps some candidate vaccines to prevent HIV infection. It is likely that some of these will be Australian discoveries,' he said.

- and IDUs—for example, the use of anonymous telephone surveys as a way of reaching homosexually active men who do not identify with the gay community or of reaching gay community members who are concerned about confidentiality;
- recognition of the primary HIV infection syndrome or seroconversion illness. The first discovery was that initial infection with HIV was associated with an illness. Later studies have suggested that the severity of this illness may influence the rapidity of subsequent clinical progression;
  - development of a rapid bedside diagnostic test for HIV infection;
  - elucidation of the mechanism of action of the HIV Nef protein. This protein appears to be required for development of the disease following HIV infection. It acts by both augmenting virus replication and directly inducing immunodeficiency. Australian investigators are one of two or three groups in the world leading this research effort;
  - characterisation of a naturally attenuated variant of HIV. A chance epidemiological occurrence was investigated to show that strains of HIV with defined genomic alterations were attenuated for humans. This observation suggests a new path to development of live, attenuated HIV vaccines and novel chemotherapeutic agents;
  - documentation of transmission of HIV by artificial insemination. Although transmission by this route was suspected, documentation of this unfortunate incident clinched the argument and has resulted in mandatory HIV testing for sperm donors;
  - establishment of the antiretrovirals clinical trials structure, where Australia has gained very substantial international recognition and has been a key participant in major international trials;
  - work relating to the HIV infection of monocytes and macrophages.

#### **6.2.4 Conclusions**

The efficiency and effectiveness of the mechanisms linking research and practice cannot be determined confidently with the available data. There are examples of collaboration and of research informing and being informed by practice. But there are also some expressions of frustration from the community sector and some State and Territory governments about the inadequacy of the current links.

There is no clear expression in the second Strategy or in any other relevant policy documents about who should take responsibility for making sure appropriate research is translated into practice. In the first instance, it would appear to be the responsibility of the funders of the research to consider policy and practice relevance at the time of funding. If a high degree of relevance is

apparent, this should be discussed with the researcher and the conditions of grant should make it clear how the research will be reported and disseminated so as to maximise its potential.

**Recommendation 40**

**It is recommended that the Commonwealth AIDS Research Grants Committee review the responsibilities that are placed on researchers either through project grants or the National Centres in HIV Research with a view to maximising the use of research and developing more effective ways of ensuring that researchers meet their responsibilities. The Committee should work with the National Centres to develop performance indicators to monitor progress towards these objectives.**

Responsibility for maximising the use of research also rests with health practitioners and policy makers. It is important that professional bodies continue to foster a culture of ‘evidence-based’ practice. One area in which this is particularly important, and in which no real professional structure exists, is among HIV/AIDS educators.

**Recommendation 41**

**It is recommended that, in examining the training needs of HIV/AIDS educators at a national level, the AIDS/Communicable Diseases Branch of the Department of Human Services and Health consider the need for educators to develop skills in using research, the need to foster a culture of ‘evidence-based’ program development among educators, and the need for educators to become partners with professional researchers in the education research process.**

The Strategy’s current concept of the relationship between research and practice is inappropriate because it implies a linear relationship between knowledge generation and knowledge use. A more sophisticated appreciation of the interaction between research and practice, and of the social context in which information is used, may lead to better ways of defining the responsibilities of funding bodies, researchers, and the practitioners or users of research. In particular, it would help the affected communities have a more central role in the research process.

## **6.3 THE RESEARCH AGENDA**

The responsiveness of the research agenda to the problems and challenges posed by HIV/AIDS is a vexed question. As noted, the different elements of the Research Program could be expected to be responsive in different ways and in different time frames.

Submissions to the evaluation often called for research in areas where there has already been a large amount of research or where research is in the

formative stages. This suggests a failure in the process of disseminating information about research in progress and research findings or a weakness in the ability of some organisations to locate research, or both.

There are legitimate calls for research that deals with HIV/AIDS/STDs among Aboriginal and Torres Strait Islander people, that poses the same questions over time and provides baseline data for measuring the performance of education and prevention interventions, that deals with broader questions of sexual health rather than being confined to HIV/AIDS, and that is conducted in and relevant to places other than the east coast of Australia.

### 6.3.1 The decline in research applications

The extent to which research can be directed by the CARG Committee or by some other process is limited. One impediment is the decline in applications for HIV/AIDS research grants. Table 6.3 shows that between 1993 and 1995 there has been a steady decline in the number of applications for funding and a dramatic drop in the number of social and behavioural research applications. This is not unique to HIV/AIDS: there has been a decline in social science applications right across the NHMRC, suggesting the presence of a larger problem.

**Table 6.3 HIV/AIDS funding applications, 1993 to 1995**

Research discipline	1993		1994		1995
	Applied	Granted	Applied	Granted	Applied <sup>a</sup>
Virology and immunology	34 (8)	13	35	14	24
Epidemiological and clinical	28 (1)	3	25	5	16
Social and behavioural	45 (3)	10	23	9	7
Total	107 (12)	26	83	28	47

a. 1995 applications are for the 1996 funding year.

Note: Numbers in parentheses are numbers of applicants from national centres who would have been ineligible in subsequent years.

Source: Commonwealth of Australia (1995).

There has been considerable disquiet and debate about how this drop in applications should be interpreted. The drop started in 1993, so it is not solely a result of the transfer of administrative arrangements to the NHMRC.

In the short and medium term, the potential for attracting high-quality research grant applications, especially in the area of social research, must be maximised. In the longer term, the role of social research within the NHMRC needs to be consolidated through deliberate measures to foster the interest of social scientists and to ensure that the relevant disciplines are given adequate scope for participation on their own terms. Both these aims could be furthered by consultation between the NHMRC and the Advisory Committee of the National Centre in HIV Social Research.

**Recommendation 42**

**It is recommended that the National Health and Medical Research Council take steps to foster high-quality social science health research, including ensuring sufficient representation of social scientists on relevant committees and in review processes.**

One reason for the decline in HIV/AIDS research applications may be the inherent limitations in focussing on HIV/AIDS to the exclusion of broader areas of sexual health, communicable diseases and public health. More researchers may be interested in conducting research into areas that, while germane to HIV/AIDS, provide a larger area of potential interest and endeavour.

From a public health perspective, there is also the question of the declining marginal benefits of researching HIV/AIDS. There is a continuing need to maintain a research effort that monitors the pattern of the epidemic in both epidemiological and social and behavioural terms, but there may be limits to which additional research can enhance the development of public health interventions.

**Recommendation 43**

**It is recommended that, in consultation with the Australian National Council on AIDS, the National Health and Medical Research Council consider redefining the scope of ‘ring-fenced’ HIV/AIDS research funds to include the broader areas of sexual health and communicable diseases.**

## **6.4 FUTURE DIRECTIONS**

### **6.4.1 ‘Ring-fenced’ funding**

An important question for 1996 and beyond is the extent to which ring-fencing of funding for HIV/AIDS project grants and training awards should continue and, if it is continued, whether all HIV/AIDS research or only certain fields should be protected in this way.

As noted, the NHMRC bases its selection on merit. But the role of the social sciences in health research has received recognition only in relatively recent times and some social scientists are concerned that HIV/AIDS social research may fail to thrive in the NHMRC structure without some special consideration. There is also concern about the extent to which the NHMRC is able to ensure that its funded research remains relevant to public health policy. It is therefore appropriate in the short and medium terms that HIV/AIDS research funds be managed in such a way as to allow their full value to public health policy to be realised.

**Recommendation 44**

**It is recommended that, in negotiating the transfer of HIV/AIDS research funds for project grants and training awards to the National Health and Medical Research Council, the Australian National Council on AIDS ensure the continued ‘ring-fencing’ of HIV/AIDS research funds until such time as this arrangement is made redundant by the increased quality and quantity of research applications and by the capacity of the National Health and Medical Research Council to foster appropriate research in this area. It is reasonable to expect this to occur over a 10-year period.**

**6.4.2 The role of the Commonwealth AIDS Research Grants Committee**

Australian HIV/AIDS research has involved a multidisciplinary response to the breadth and complexity of the problems and challenges raised by HIV/AIDS. The CARG Committee process has provided a mechanism for looking at the spectrum of research on HIV/AIDS, identifying areas needing extra attention or increased cooperation, and making recommendations that these matters be attended to. It has not always been successful in ensuring that project grants were made in the areas identified, even though it has used a variety of mechanisms at different times. It has, however, been very successful in relation to the work done by the National Centres. Submissions to the evaluation expressed concern lest this capacity be lost in the general transfer to the NHMRC since there is no equivalent mechanism within the NHMRC to oversee particular areas of research from a public health policy perspective.

The second Strategy envisaged that a new body would be established in 1994 to act as a management committee for the three National Centres in HIV Research. It was to be known as the HIV/AIDS National Research Centres Management Committee. It has not been formed and the CARG Committee has largely taken on its function. This should be endorsed by ANCA. The CARG Committee should not have a role in the assessment of project grant applications: this would make the project grant application process too cumbersome.

**Recommendation 45**

**It is recommended that, as part of a third National HIV/AIDS Strategy, the Australian National Council on AIDS review the Commonwealth AIDS Research Grants Committee’s terms of reference and endorse its role in overseeing the work of the three National Centres in HIV Research.**

The plan to transfer the administration of the three National Centres to the NHMRC should be reconsidered. The National Centre in HIV Virology Research appears to be well placed to be absorbed into the NHMRC. But the case for incorporating the other two National Centres to the NHMRC is not

## **SOCIAL RESEARCH—THE KEY TO BEHAVIOUR**

'Transitions' is a major report to be released later this year; it looks at people living with HIV who have moved to AIDS and is based on the words and experiences of affected people.

According to the author of the report, long-time HIV/AIDS activist Bill O'Loughlin from Victoria, there are some very moving stories among the interviews. 'With so many more people living longer with HIV, I believe this is a very important piece of social research that can help shape future policies that affect people with HIV and AIDS,' he said. 'In the study we talked to people who had had AIDS for a long time and to people who had just moved into the AIDS stage, or who had a gut feeling that things were changing in their bodies,' Bill explained. 'Sadly, many of our subjects are now dead—being HIV-positive myself, it has been quite traumatic for me personally.'

Bill has been working on the report for almost two years and is very certain about the value of social research in determining the right directions for policy makers and service providers. 'For example, in our study we talked to people who, with HIV, belonged to people living with HIV/AIDS groups and they were settled and well adjusted, but now they have progressed to AIDS they are confronted with issues they could not prepare for. We found there was a lot of uncertainty out there—the uncertain nature of the disease process; some people have been sick non-stop for years, while others have had only intermittent illness.

'Then there was the shift from being an active person into a world that is really only focussing on relationships with medical systems and doctors, and there was the inevitable scaling-down of life activities. We found that people often get very worried about their appearance: they talk about "the look"—"I've got the look of AIDS"—people find this very traumatic.

Bill is concerned that social research into HIV/AIDS is now in a state of flux. 'In the early days of the virus a lot of social research that was done in Australia was of world standard, but the community is now saying there is a need to see research undertaken that links up with those in the community who need to put policies, which come out of the report, into practice. They also want the research to be relevant,' he said.

Bill said social research is important to give governments and health planners a detailed understanding of what people are doing. 'For example, in sexual behaviour it gives us an understanding of the complexities of people putting safe sex ideas into practice. It tells us the directions we need to be going in education, treatment and care and the areas where we need to be paying attention.'

As the newly elected president of the Australian Federation of AIDS Organisations—the peak body representing non-government AIDS organisations—Bill said he is looking forward to having a real influence on the direction of social research into HIV/AIDS in Australia into the next century.

strong. These Centres are unlike other national research units funded through the NHMRC and they perform functions that are essential to the successful management of the HIV/AIDS epidemic in Australia. They should be administered in a way that reflects this.

**Recommendation 46**

**It is recommended that the administration of the National Centre in HIV Social Research and the National Centre in HIV Epidemiology and Clinical Research be located within the AIDS/Communicable Diseases Branch of the Department of Human Services and Health for the duration of the current agreements. In the longer term their administrative arrangements should match their purpose as instruments of public health policy and practice.**

### **6.4.3 Other funding matters**

The transfer of HIV/AIDS research project grants and training awards to the NHMRC is appropriate, if the safeguards just discussed apply, but there are some functions that appear to require continuing funding through a program administered by the AIDS/Communicable Diseases Branch under a third Strategy.

First, there is the National HIV Reference Laboratory. The Laboratory has been funded by the Commonwealth since 1985 to ensure a high standard of HIV testing in Australia through the evaluation of HIV test assays and the coordination of a national laboratory quality-control and quality-assurance program. In the context of this evaluation an independent review of the National HIV Reference Laboratory was begun in December 1994. The review concluded that it was essential to maintain the national reference function for HIV/AIDS serodiagnostics but recommended that, within the same budget parameters, the Laboratory be restructured and refocussed to deal with quality questions pertaining to other serodiagnostics. The Minister for Human Services and Health accepted and endorsed the final report of the review in April 1995.

It is appropriate that the National HIV Reference Laboratory be viewed as having a public health function directly related to the management of national diagnostic policy and practice for HIV/AIDS and other communicable diseases and that it be funded as such rather than as a component of research.

Second, CARG funds have enabled the Department of Human Services and Health to commission studies to investigate specific and immediate public health problems in relation to HIV/AIDS. This flexibility to respond quickly to emerging problems or issues is not currently available through the NHMRC and will be lost unless some funds are retained for that purpose.

**Recommendation 47**

**It is recommended that funding for aspects of the Research Program related to the operation of the National HIV Reference Laboratory and for enabling the Department of Human Services and Health to respond quickly to emerging public health problems in communicable diseases be incorporated in funding for a third National HIV/AIDS Strategy.**

# Looking outwards— the International Assistance and Cooperation Program

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The goal of the International Assistance and Cooperation Program is to contribute to limiting the incidence and impact of HIV/AIDS globally with a particular focus on the Asia/Pacific region, through participating in international policy development and implementation and assisting in policy and program development at a country level, drawing on the broad range of expertise, commodities and services available in Australia which are appropriate to the needs of developing countries. (Commonwealth of Australia 1993a, p. 33).

## 7.1 BACKGROUND

The HIV/AIDS pandemic is spreading rapidly through the developing world. In 1990 an estimated 80 per cent of all new infections were occurring in developing countries and this has been predicted to rise to 95 per cent by the year 2000 (World Bank 1993). The majority of these infections have resulted from heterosexual contact and the incidence of infections among women of child-bearing age is rising steeply.

The worst affected area is sub-Saharan Africa—with an estimated 11 million people infected with HIV by mid-1995—but the most alarming trends are now



in southern and south-eastern Asia. Although extensive spread of HIV in this region began only in the mid-1980s, an estimated 3.5 million adults were infected by mid-1995, up from 2.5 million in mid-1994 (WHO 1995).

Reported infection rates in the Pacific nations and Papua New Guinea are low. But testing levels in these countries are also low, which suggests that available figures underestimate the extent of infection in this region.

The inclusion of the International Assistance and Cooperation Program in the National HIV/AIDS Strategy is an acknowledgment that HIV is a pandemic and that efforts to control its spread domestically cannot be made in isolation from international efforts to contain the disease. It is also testimony to Australia's humanitarian commitment to help poorer nations cope with the impact of HIV and to prevent its further spread.

The Program has seven guiding principles: improved management and coordination at global and regional levels; consistency with the partnership approach; a focus on the Asia-Pacific region; the importance of guidance from the recipient countries in relation to their specific needs; recognition of the low status of women; assistance with program planning and national staff skills development; and recognition that an effective response to HIV/AIDS requires integration with other development challenges and a supportive social and legal environment.

Three broad areas of international response are identified in the Strategy: international policy development and implementation; bilateral (government-to-government) and regional programming; and a range of other activities, including participation in multilateral programs, academic, professional and non-government organisation (NGO) exchanges, private sector training, secondments, and commercial contracts for commodities.

The Program also identifies three government agencies as responsible for supporting Australia's international response: the Australian Agency for International Development (AusAID—previously known as the Australian International Development Assistance Bureau, or AIDAB); the Department of Human Services and Health; and the Department of Foreign Affairs and Trade.

AusAID is identified in the second Strategy as the agency that had provided, and would continue to provide, most of the financial support for international HIV/AIDS programs. It spent an estimated \$14.02 million in 1994–95, up from \$6.14 million in 1992–93 (see Table 7.1).

AusAID delivers international HIV/AIDS assistance through individual country and regional bilateral programs, multilateral agencies, and NGOs. Among the agencies and organisations receiving funding in 1994–95 were the WHO Global Program on AIDS and the Joint United Nations Programme on AIDS (UNAIDS), the United Nations Development Programme, the South Pacific Commission, UNICEF, AFAO, the Australian Council for Overseas Aid, the Australian Red Cross Society, World Vision, Community Aid Abroad, the Adventist Development and Relief Agency, and Quaker Service Australia.

**Table 7.1 AusAID expenditure on international HIV/AIDS programs, 1992–93 to 1994–95**

Program coverage	(\$'000)		
	1992–93	1993–94	1994–95 (est.)
Global	1 000	1 430	2 450
SE Asia regional	3 020	1 910	2 430
Other Asia	560	1 830	5 980
South Pacific/PNG	660	330	1 280
Africa	900	1 150	1 880
Total	6 140	6 650	14 020

Source: AusAID (Submission 54).

HIV/AIDS projects delivered by NGOs are funded by AusAID through a variety of programs, each with its own eligibility and selection criteria. There were some concerns raised in consultations about whether all of these criteria are flexible enough to enable participation by domestic NGOs specialising in HIV/AIDS. AusAID is currently considering the recommendations of a review of the roles of NGOs in the aid program, and may make changes to the administration of this sector.

The Department of Human Services and Health is identified in the Strategy as the agency responsible for supporting and promoting development of Australia's capacity to participate at all levels in international programs and for providing expert technical and policy advice. It has established in the AIDS/Communicable Diseases Branch an International Unit, which expanded from one officer in 1992 to four in 1994. International program expenditure has increased from \$289 000 in 1993–94 to an estimated \$314 000 in 1994–95. In both years, \$200 000 of this was for the secondment of a departmental officer to the Global Program on AIDS.

The Department has had three main areas of international activity under the current Strategy: it has provided policy advice and briefings on HIV/AIDS matters in international forums; it has initiated and developed bilateral and non-governmental links with countries within the region to contribute to the regional response; and it has contributed to the development of networks and information sharing in the region. Examples of specific activities are briefings and coordination with the Global Program on AIDS and other United Nations bodies, including through secondment of a departmental officer to the Global Program's Task Force on HIV/AIDS Coordination; advice on technical matters and presentations to visitors from Asia; input to a study tour of Thailand by senior officials from the Government of Vietnam; short-term placements of officers in overseas countries; participation in the 'Australia Today Indonesia 1994' exposition; and support for the Australia–Indonesia Institute Fellowship of a Member of the Indonesian Parliament.

The Department of Foreign Affairs and Trade has no designated resources for its HIV/AIDS work, funding its activities in this area from its general budget. Its responsibilities identified under the Strategy are the provision of policy advice, collection and collation of international information, and coordination of international policy development and implementation. The Department's activities under the current Strategy include statements on HIV and discrimination to the Commission on Human Rights in 1993 and 1994, development of a Human Rights National Action Plan, and the production of country profiles for use by those working in Asia and the Pacific.

## **7.2 INTERNATIONAL POLICY DEVELOPMENT AND IMPLEMENTATION**

In spite of the fact that Australia is a relatively small donor to the United Nations effort, it has had considerable influence in the international HIV/AIDS arena, particularly in relation to the Global Program on AIDS and the development of its successor, UNAIDS.

There have been a number of reasons for this, among them the effective involvement of Australia's Ambassador to the United Nations in negotiations leading to the establishment of UNAIDS, the involvement of a seconded officer from the AIDS/Communicable Diseases Branch in the Global Program on AIDS Task Force and then the UNAIDS secretariat; and international recognition of Australia's success in dealing with the domestic epidemic through a partnership approach based on community empowerment.

Australia has also provided financial and other support to a number of regional networks, including the Asia-Pacific Council of AIDS Service Organisations, which has contributed to the International Council of AIDS Service Organisations.

For both humanitarian and national-interest reasons it is important that Australia continues to participate in global forums, including UNAIDS and United Nations Development Program. Australia's funding of a policy position at the new World Bank Regional Project in Bangkok is a positive development.

### **Recommendation 48**

**It is recommended that Australia continue to play an active role in international policy development and implementation through participation in United Nations and other international forums and activities.**

## NEAR NEIGHBOURS NEED HELP WITH HIV

With so many developing countries close to Australia gradually coming to terms with the HIV/AIDS pandemic, many individuals and organisations in the region are looking to Australia for guidance, advice and some practical assistance.

Much of this work is shouldered by HIDNA—the HIV/AIDS International Development Network of Australia—a joint project of the Australian Federation of AIDS Organisations and the Australian Council for Overseas Aid. Phil Marshall, a former employee of Foreign Affairs in New Zealand, is coordinator of HIDNA and the work of his small team encompasses a range of activities, from conducting training sessions for Australians dealing with overseas countries to arranging special-issue seminars on current issues in HIV/AIDS and development.

‘The aim of the project is to bring people together, to share information and to set up networks that will assist them in their work with overseas countries,’ Phil explained. ‘Initially we brought together the development organisations and the HIV/AIDS organisations. It has now evolved into something bigger, with the Federal Government participating and medical and research organisations also linking into our network.’

Phil said one of the most important lessons Australia can impart to developing countries is how we have gone about promoting behaviour change in people at risk of contracting the virus. ‘But we just can’t transpose the Australian experience to other countries where cultural, religious and political systems are so different from ours. We can only share our experiences and assist and advise when asked,’ he said.

Being such a small organisation—only one and a half full time employees—HIDNA relies heavily on forging links with similar groups overseas. ‘There are about seven organisations like HIDNA around the world and we keep close contact with them and network extensively with many other organisations,’ he said. ‘Through these links we aim to lobby governments and multilateral organisations around the world to support the work of community groups with appropriate policies.’

Phil said overseas countries’ impressions of Australia’s response to HIV/AIDS vary, depending on the people they meet from Australia. ‘It’s important that Australians who will be dealing with overseas countries about HIV/AIDS have some understanding of the different environments in which they will be working. For example, in many developing countries women are being infected at similar rates to men and the majority of these women are infected by their husbands. Promoting safe sex between married couples may not be a feasible option, particularly when there are often pressing concerns about food, shelter and more visible health issues,’ he explained. ‘The last thing developing countries need is for Australia to try to impose its ideas onto them.’

Phil said many overseas people are very interested in the way in which governments, the medical and research community, and the affected community have worked so well together to respond to the epidemic in Australia.

‘For example, at the World AIDS conference in Chiang Mai in Thailand later this year, HIDNA is coordinating the Australian stand, which will contain information provided by the Federal Government, the Australian medical profession, and a range of community groups affected by HIV. The theme of the stand will be people working together to effectively respond to the epidemic,’ he said.

### 7.3 REGIONAL AND COUNTRY PROGRAMS

Table 7.2 summarises an inventory of Australian organisations working with HIV/AIDS in developing countries in 1995; the inventory was produced by the HIV/AIDS International Development Network of Australia. In addition to the projects shown, the inventory identifies a number of projects that have been completed in South-East Asia (13), the Pacific (four) and Africa (three) and projects under consideration in South-East Asia (10), the Pacific (one), Asia (one) and Africa (three). Among the agencies involved in the completed and planned projects are some of those shown in Table 7.2 but also African Enterprise, the AIDS Society of Asia and the Pacific, Cumberland College of Health Sciences, Family Planning Australia, and the National Centre in HIV Epidemiology and Clinical Research.

**Table 7.2 Number of international HIV/AIDS projects supported by Australian agencies, by location of project, 1995**

Agency	SE		Pacific	Africa	South		Total
	Asia	PNG			Asia	America	
Adventist Development and Relief Agency	1	1					2
Australian Federation of AIDS Organisations	8		1				9
Australian People for Health, Education and Development Abroad	5		1	1			7
Archbishop of Melbourne's International Relief and Development Fund				1			1
Austcare	1	1					2
Australian Baptist World Aid	2	1		1			4
Community Aid Abroad	1	2		1			4
CARE Australia	7			1			8
Cumberland Foundation			1				1
International Women's Development Agency	1						1
Macfarlane Burnet Centre for Medical Research					1		1
Overseas Service Bureau	4	1		1	3	2	11
Quaker Service Australia	1			1	1		3
Salvation Army				7	1		8
Save the Children Fund	2		2		1		5
Tear Australia	1			4	3		8
UNICEF (Australia)	1		1	2	1		5
World Vision (Australia)	6	1	1	2	3		13
Total	41	7	7	22	14	2	93

Source: HIV/AIDS International Development Network of Australia (1995).

Since the inventory was based on voluntary completion of a survey instrument sent to known and possible participants in the international arena, it does not provide a complete overview of international activity. Funding for the projects shown in the table comes from a range of sources, including AusAID.

## 7.4 OTHER ACTIVITIES

There is a wide range of other work being done by individuals and organisations in the international arena. The activities of some of the agencies and organisations are summarised in this section: the summary is not exhaustive.

The National Reference Laboratory has provided confirmatory testing, quality assurance for reference laboratories in the region, information and training. Staff have also acted as consultants in a range of international forums. Following a review in 1995, the Laboratory's international role will probably change, as discussed in Section 8.1.3.

ANCA has selectively participated in international forums, making members available to speak with visiting delegations or experts from other countries. It has provided advice and expertise in prevention, care, surveillance and research, national policy formulation, and public information initiatives.

AFAO is active internationally in a number of ways: partnerships with community-based projects in Asia and the Pacific; membership of the Asia-Pacific Council of AIDS Organisations; co-sponsorship of and participation in the HIV/AIDS International Development Network of Australia; policy development and advocacy at national, regional and global levels with the Department of Human Services and Health, AusAID and the Department of Foreign Affairs and Trade; information exchange with international visitors; participation in regional HIV legal networks; and the organisation and conduct of study tours and training of international visitors.

The international activities of the National Centre in HIV Epidemiology and Clinical Research have focussed on the Pacific Rim and include the following: advice to visiting medical and scientific delegations; participation in the Global Program on AIDS and other international advisory and steering committees; WHO consultancies; private and sponsored visits to selected countries; formulation of projects that require external funding; and collaborative research projects with research organisations in the region.

In addition to the specific projects shown in Table 7.2, the Macfarlane Burnet Centre for Medical Research has been involved in project design, evaluation, materials preparation and consultancies for a range of national and international organisations across the Asia-Pacific region. The Centre's activities range from individual consulting to NGO partnerships and bilateral and multilateral projects. A small proportion of the funding for these activities is received from AusAID and the remainder comes from contracts and consultancies.

Members of the International Working Group established by the former National Centre in HIV Social Research have contributed to Australia's international response through consultancies and other work for both the

Global Program on AIDS and the United Nations Development Program, through presentations at HIV/AIDS and STD international conferences, and through involvement in HIV projects in the region. In 1994 it held a seminar for social scientists in the region to discuss the emerging social research issues.

The Centre for Research in Public Health and Nursing has developed a network and newsletter for nurses in the region, helped with the development of protocols and models of care, provided information and given advice on infection control, and developed collaborative research projects.

State and Territory health departments, members of the Australasian Society for HIV/AIDS Medicine, and individual experts are also active in a variety of capacities in the international arena.

In general, activities under the International Assistance and Cooperation Program have focussed on the Asia–Pacific region and there are good reasons why this focus should be maintained. The regional HIV/AIDS pandemic has health, economic and political implications for Australia because of our expanding tourist and business links with countries in Asia and the Pacific. By focussing on the local region, Australia also has a greater capacity to develop the relevant experience and expertise and to implement a more strategic, concentrated and coordinated aid effort.

#### **Recommendation 49**

**It is recommended that Australia continue to focus its international assistance effort on the Asia–Pacific region.**

## **7.5 SCOPE AND FUNDING**

The current Strategy does not adequately describe the scope of the International Assistance and Cooperation Program. The Program may best be described as a set of activities undertaken in the international arena by various agencies and individuals, both government and non-government, whose common link is that they aim to contribute to the Program's goal. The activities are funded in a number of different ways, including fund raising, competitive grants, contracts and consultancies. A third Strategy should better acknowledge the diversity of players, activities and funding sources that make up Australia's international response. This would allow for greater coordination and communication.

#### **Recommendation 50**

**It is recommended that a third National HIV/AIDS Strategy better acknowledge the diversity of players, activities and funding sources that contribute to the International Assistance and Cooperation Program.**

## 7.6 LEADERSHIP AND COORDINATION

A program as diverse as the International Assistance and Cooperation Program calls for leadership and coordination. The first National HIV/AIDS Strategy addressed the need for cooperation and communication between the three key government agencies (AusAID, the Department of Human Services and Health and the Department of Foreign Affairs and Trade) and recommended the establishment of an interdepartmental committee to coordinate their international activities. The Department of Human Services and Health and AusAID agreed, however, that such a committee was not appropriate given the size of the budget for international activities relating to HIV/AIDS at that time. Instead, a process of voluntary liaison was developed between the agencies, each of which was seen as having specialist expertise to contribute to the international response.

Under the current Strategy, high priority has been given to developing good working relationships between the three agencies and substantial gains have been made. Some formal links have been established, such as the Department of Human Services and Health representation on selection panels for AusAID program funding. The Department also worked closely with AusAID to develop a bilateral assistance project to Indonesia.

Overall, though, interaction between the three agencies has been largely informal and dependent on the will and effort of individuals. This has meant that a large amount of time has been spent negotiating areas of responsibility. Heavy dependence on the activities of individuals also raises questions of sustainability, should there be changes in the duties of those people. Further, the NGO sector reported some confusion about the roles of the government agencies, particularly AusAID and the Department of Human Services and Health.

In addition to the problems with coordination, there has been a lack of leadership, with no agency or group identified as taking a leading role in shaping the direction of the Program. Among other things, this has hindered the flow of information, making it difficult for many of those involved to keep abreast of developments and exchange information.

Since it is widely accepted that the three Commonwealth agencies have different and complementary skills and responsibilities in the international arena, a tripartite arrangement to provide leadership and coordination should be developed. One of the earliest tasks of this interdepartmental committee should be to formally clarify roles and responsibilities and these should be explained to NGOs and individuals.

### **Recommendation 51**

**It is recommended that an interdepartmental committee comprising representatives of the Department of Human Services and Health,**

**AusAID and the Department of Foreign Affairs and Trade be established to provide leadership and coordination for the International Assistance and Cooperation Program.**

Inclusion of an international program in the National HIV/AIDS Strategy signals Australia's commitment to playing a role in the regional and global effort to contain the pandemic; the International Assistance and Cooperation Program has provided a broad framework for that effort. As the range and scope of Australia's activities expand, however, there is a need for a more strategic program that has specific objectives and priorities and provides a clearer delineation of roles and responsibilities. A consultative approach to the development of a more strategic program will help to ensure a sense of ownership among participants.

Australia's international projects have to some extent focussed on education and prevention. As the pandemic evolves, greater attention will need to be given to treatment and care, in which Australia is recognised as having considerable expertise. Australian medical, nursing and allied health professionals all have the potential to play a stronger overseas role in this regard.

A number of other factors need to be considered in the development of a more strategic program. Changes in the distribution of HIV/AIDS in the region and social and cultural differences in the groups most affected will have an impact on the need for and focus of aid activities. Similarly, changes in the domestic capacity of overseas countries to deal with the epidemic and the relative amounts of funding going to affected countries need to be considered when limited resources are being allocated. Greater integration of HIV/AIDS activities into other development initiatives should also be considered, as should the need for a balance between bilateral and NGO projects and activities. All these factors are dynamic, so a more strategic program will have to be able to recognise and respond to changes over time.

The program must also continue to recognise the relevance and importance of human rights, the status of women, poverty, and the legal, moral and religious aspects of Australia's international response to HIV/AIDS.

The development of a more strategic program for Australia's international activities is beyond the brief of the National HIV/AIDS Strategy. It should be undertaken by the proposed interdepartmental committee.

**Recommendation 52**

**It is recommended that the proposed interdepartmental committee develop a work plan that takes a more strategic approach to Australia's International Assistance and Cooperation Program and clarifies specific objectives and priorities.**

## **7.7 PARTNERSHIPS**

The partnership approach, internationally recognised as a strength of Australia's domestic response to HIV/AIDS, has been successfully extended to the international arena. Support for and the involvement of NGOs have been an important part of this approach. Future development of the Program should build on the strengths of partnerships, including those with agencies and organisations in overseas countries.

Mechanisms for communication and information exchange are essential to the process of building and maintaining partnerships. An important initiative in this regard has been the establishment of the HIV/AIDS International Development Network of Australia in July 1992 as a joint project between the Australian Council for Overseas Aid and AFAO. The Network is funded by the Department of Human Services and Health, AusAID and member contributions and has facilitated inter-agency cooperation, skills development and information exchange.

The presence of government officers as observers at Network meetings has provided a mechanism for interaction between the government and non-government sectors. Examples of collaborative activities are the project design manual developed by the Macfarlane Burnet Centre for Medical Research and the Department of Foreign Affairs and Trade country profiles, both of which are resources for the NGO sector.

The Network also has links with similar networks in North America and Europe and with other international networks, including the Asia-Pacific Council of AIDS Service Organisations and the Global Network of People with HIV/AIDS.

Given the diversity of participants in the International Assistance and Cooperation Program, the Network can be expected to make only a minor contribution to communication and information exchange. As part of its leadership role the proposed interdepartmental committee should provide more information about the scope and nature of Australia's international activities and guidance on the type of interventions and assistance that would complement other program activities.

## **7.8 PUBLIC HEALTH PRACTICE IN INTERNATIONAL SETTINGS**

Although the diversity of individuals and organisations working overseas under the broad umbrella of the International Assistance and Cooperation Program is to be encouraged, questions have been raised in Australia about the quality and appropriateness of some Australian activity overseas.

AusAID's funding guidelines and selection procedures provide a mechanism for screening some NGO projects. There are, however, many other overseas

activities that are not subject to a formal selection process. Thus important questions relating to the transferability of Australian approaches and technologies (including their cultural and economic appropriateness) and the incorporation of development principles in project design and implementation may not always receive the attention needed to ensure that program activities are effective.

Additional mechanisms should be developed to help ensure that Australia's international activities are of the highest possible standards. Given the complexity of the International Assistance and Cooperation Program, additional screening procedures or systems of accreditation would probably be obstructive. A more useful approach would be to devise a set of guidelines that identifies the elements of best practice in an international setting. The guidelines should be developed under the direction of the proposed interdepartmental committee, with the full involvement of participants in the international arena. This will help to ensure ownership of the guidelines by those for whom they are intended, and it will increase the likelihood that they will be used as a voluntary code of practice. Once developed, the guidelines should be widely disseminated, including in the overseas countries in which Australians are working.

### **Recommendation 53**

**It is recommended that the proposed interdepartmental committee develop a set of best practice guidelines for the International Assistance and Cooperation Program.**

A second way to help ensure the effectiveness of Australian international activities is through evaluation. Although some of Australia's international activities (including projects funded by AusAID) have an evaluation component, the focus has mainly been on process and formal assessment of impacts or outcomes has been limited. Since the activities are so diverse, it is not possible for the International Assistance and Cooperation Program to provide a framework for their evaluation. A third National HIV/AIDs Strategy should, however, emphasise the importance of impact and outcome evaluation. As part of Australia's commitment to capacity building in overseas countries, local participants should be involved to the fullest extent possible in these evaluations, both as evaluators and as project recipients whose views are sought as part of the evaluative research.

Evaluations have resource implications and their costs should be built into project funding. The proposed interdepartmental committee should also establish a mechanism for wide dissemination of evaluation findings, so that a body of information about what works and what doesn't work is progressively developed and made available to Program participants.

**Recommendation 54**

**It is recommended that a third National HIV/AIDS Strategy emphasise the importance of impact and outcome evaluations of International Assistance and Cooperation Program activities. A mechanism for the dissemination of evaluation findings should be established.**

**7.9 RESEARCH**

Even though research has been an important part of Australia's domestic response to HIV/AIDS, it has received limited recognition or support in the international arena.

If effective interventions are to be developed, information is needed on the social, cultural and political context within which behaviours occur and through which interventions are mediated. Data on the spread of infection are needed to evaluate the effects of preventive programs. Research on treatment and care will assist in the development of optimal approaches to management in international settings.

Australian researchers do have a contribution to make in international social, nursing, medical, epidemiological and policy research, including basic monitoring of the spread of HIV. Local collaboration and participation in such research would result in skills transfer to local researchers, enhancing their capacity to do their own work.

In developing a third National HIV/AIDS Strategy, recognition should be given to the role of research that is relevant to the International Assistance and Cooperation Program. Funding sources for overseas research may need to be identified.

**Recommendation 55**

**It is recommended that a third National HIV/AIDS Strategy recognise the importance of research that is relevant to the International Assistance and Cooperation Program.**

**7.10 METHODOLOGY**

Information about the International Assistance and Cooperation Program was obtained from selected documents, meetings with departmental representatives, written submissions, telephone and face-to-face interviews with key informants, and voluntary completion of a survey mailed to organisations selected from the HIV/AIDS International Development Network of Australia database. The following organisations and individuals participated in one or more of these processes: Professor D Altman, the Archbishop of Melbourne's International Relief and Development Fund, Austcare, AusAID, Australian Catholic Relief, the Australian Council for Overseas Aid, AFAO, ANCA, the

Australian Red Cross, the Australasian Society for HIV/AIDS Medicine, Mr P Bluett, Care Australia, the Catholic AIDS Ministry, the Centre for Research in Public Health and Nursing, the Centre for the Study of STDs, Community Aid Abroad, the Department of Foreign Affairs and Trade, the Department of Human Services and Health, the HIV/AIDS Development Network of Australia, the International Women's Development Agency, the International Working Group of the National Centre in HIV/AIDS Social Research, the Macfarlane Burnet Centre, the National Centre in HIV Epidemiology and Clinical Research, the National Reference Laboratory, Quaker Service Australia, the CAPE Centre, and World Vision Australia.

A limited amount of information about the Program was also obtained from submissions to the evaluation. The names of these submitters are not listed here.

# Discrimination and the legal environment

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The importance of a supportive legal environment to the success of the National HIV/AIDS Program is well recognised. The first National HIV/AIDS Strategy identified the need for legislative reform in light of the challenges that HIV/AIDS presented to existing laws and traditional public health approaches. The widespread legal, ethical, social and political ramifications of the HIV/AIDS epidemic have made it necessary to review some laws that have relevance well beyond this particular viral infection.

For instance, educating gay men about safe sex is difficult if homosexual activities are subject to criminal penalties. And injecting drug users are unlikely to use needle and syringe exchange programs if this leaves them open to criminal prosecution. Nineteenth-century public health and quarantine measures providing the power to imprison and remove infected individuals will not encourage individuals to test and seek treatment for their infection. Great advances in removing these and other barriers to the successful implementation of public health programs have been achieved in the past 13 years.

## 8.1 BACKGROUND

In February 1990 a Legal Working Party (LWP) was established as a sub-committee of the Intergovernmental Committee on AIDS to review legislation impinging on HIV/AIDS and make recommendations for uniform national law reform. The adequacy of the Commonwealth's *Privacy Act 1988* in protecting HIV/AIDS-related information was also reviewed by the Privacy and HIV/AIDS Working Party.

The LWP report made 89 recommendations for law reform in the areas of public health, civil liability, discrimination, homosexuality, prostitution, employment law, injecting drug use, therapeutic goods, and broadcasting and censorship (Commonwealth of Australia 1992a).

The LWP report, together with the report of the Privacy and HIV/AIDS Working Party (Commonwealth of Australia 1992b) and the introduction of the *Disability Discrimination Act 1992* (which covers people with HIV/AIDS), constitute important achievements under the first Strategy.

The LWP and the Commonwealth consider that the LWP's final report provides a policy blueprint for uniform national law reform. The IGCA and Australian Health Ministers Advisory Council unanimously endorsed the report's recommendations but acknowledged that the 'in principle' adoption of

the recommendations by a particular jurisdiction did not commit the government of that jurisdiction to immediate implementation of the recommendations. The priorities and needs of the various jurisdictions differ and there are also differences in the respective legislative environments. The LWP attempted to provide the ideas, arguments and evidence to show what it believed should be done to help manage the HIV/AIDS epidemic.

As recognised in the second Strategy, responsibility for implementation of the majority of the LWP's recommendations rests with the attorney-general's departments of the various jurisdictions in consultation with relevant portfolios.

In September 1993, a Commonwealth Implementation Working Group was established by the Ministers for Justice and Health. Initially the Group's mandate was to oversee implementation of the LWP's recommendations, monitor compliance with the guidelines of the Privacy and HIV/AIDS Working Party, and advise the Commonwealth Government on legal and administrative reforms relevant to HIV/AIDS. Resource limitations led the Group to revise its brief, and it nominated superannuation and privacy as priority areas for Commonwealth action. It felt that these were areas in which it could have the greatest impact.

The Implementation Working Group is chaired by a senior member of the Office of the Federal Minister for Justice and contains members from the Office of the Federal Minister for Human Services and Health, the Department of Human Services and Health, the Department of the Attorney-General, AFAO, ANCA and the IGCA.

The second Strategy noted that the IGCA will continue to have a role in facilitating implementation of the LWP's recommendations and monitoring government policies that are a hindrance to HIV/AIDS prevention efforts. Other members of the partnership will also have a role in providing feedback on the policies and legislation that bear on the course of the epidemic and the welfare of those affected by it. In particular, the Strategy identified the need for all members of the partnership to find ways of reducing disadvantage experienced by people living with HIV/AIDS and the need for the Commonwealth to monitor the impact of the Disability Discrimination Act and the Privacy Act.

## **8.2 GENERAL EFFECTIVENESS OF LAW REFORM PROPOSALS**

Decisions to reform the law are made by State and Territory and Commonwealth Ministers. The Implementation Working Group facilitates implementation of the LWP's recommendations by monitoring developments and by keeping HIV/AIDS law reform on the agenda of ministerial forums such as the Standing Committee of Attorneys-General, the Australian Police Ministers Conference, and the IGCA.

One important activity of the Implementation Working Group has been the production of a status report, which describes the extent of implementation in each jurisdiction. It has been prepared in cooperation with the departments responsible for health and law in the States and Territories. The status report will be released in late 1995 and supplied to ministerial forums. (It is a source of information for this chapter.)

Bodies comparable with the Implementation Working Group have been established in New South Wales and South Australia to monitor and review the implementation of law reform in those jurisdictions. Both bodies have published major reports on the extent and appropriateness of implementation of the LWP's recommendations. The departments responsible for health in Victoria, Queensland, the Australian Capital Territory and Tasmania have prepared internal, unpublished reports on the current level of implementation of the recommendations.

At the Commonwealth level, leadership has been critical in several areas of law reform and administration. For example, a major achievement in the area of employment law has been the development and adoption by the States and Territories of a National Code of Practice for Health Care Workers and Others at Risk of Transmission of HIV and Hepatitis B in the Workplace, which is legally binding in all but one jurisdiction. The two areas in which there has been only limited success in implementing the LWP's recommendations are media law and therapeutic goods.

In the States and Territories the most active period of law reform occurred during the LWP review period, 1990 to 1992. Jurisdictions were active in enacting new laws (for example, anti-discrimination legislation) and in modifying existing laws (for example, public health legislation). Since the release of the LWP's final report in November 1992 reform initiatives have been less dramatic and more in the nature of single jurisdictions catching up with other jurisdictions (for example, Western Australia introduced laws protecting needle and syringe exchanges).



Although some State and Territory reform initiatives have been innovative, others have reversed the recommended policy of the LWP. Examples of innovative reform are found in New South Wales legislation prohibiting vilification on the grounds of HIV/AIDS and the Australian Capital Territory's legal recognition of same-sex relationships. Three jurisdictions have recriminalised aspects of prostitution, providing examples of the reversal of the LWP's recommendations. There have also been instances of jurisdictions reforming areas of legislation not considered by the LWP (for example, the Northern Territory's Euthanasia Act).

## **8.3 SPECIFIC IMPLEMENTATION IN PRIORITY AREAS**

### **8.3.1 Privacy**

In September 1992 the Privacy and HIV/AIDS Working Party issued privacy guidelines, which are applicable to Commonwealth and Australian Capital Territory government agencies. The Implementation Working Group and the Privacy Commissioner's Office are currently consulting as part of a review of the guidelines. The consultation process has revealed that the biggest problems are lack of awareness of and compliance with the guidelines. An example of best practice may be found in the Department of Social Security, which has provided extensive staff training. When the review is completed in late 1995 the Implementation Working Group will consider whether to recommend to government that the guidelines be given a legislative basis.

Tasmania is the only jurisdiction that has implemented the LWP recommendation that the States and Territories adopt the privacy guidelines.

### **8.3.2 Superannuation and insurance**

Since the Implementation Working Group's inception an important area of activity has been negotiations with the superannuation industry about discriminatory exclusion clauses in group superannuation schemes for death and disability cover. The 1993 Trowbridge report on HIV/AIDS superannuation and insurance found that HIV/AIDS-specific exclusion clauses were not justified by the available actuarial data and statistical evidence. National Mutual, Life Reinsurance of Australia Ltd and AMP removed the exclusion clauses in late 1994 – early 1995.

The Implementation Working Group has commissioned a review of the life insurance and superannuation codes of practice; this will involve extensive consultation with individuals and associations. The review will develop general principles applicable to other areas of insurance.

### 8.3.3 Anti-discrimination legislation and homosexuality

The Commonwealth's *Disability Discrimination Act 1992* makes discrimination on the basis of disability illegal in most instances. 'Disability' is defined so as to include discrimination on the basis of known or imputed HIV status.

All jurisdictions except Tasmania have implemented anti-discrimination legislation broadly consistent with that recommended by the LWP. In New South Wales the legislation has been reviewed extensively and extended to include vilification on the grounds of HIV/AIDS and homosexuality. New South Wales is also reviewing its Anti-Discrimination Act as a whole and is carrying out a general review of laws that fail to recognise homosexual relationships; the New South Wales Government has indicated its intention to adopt provisions similar to those in legislation in the Australian Capital Territory concerning such relationships. The New South Wales Government has also formally announced its intention to enact amendments to anti-discrimination legislation to prohibit discrimination against people of transgender orientation. A review of Victorian anti-discrimination legislation resulted in a new Act being passed in 1995, prohibiting discrimination on the grounds of homosexuality except in work involving the care and instruction of children (similar to provisions in Queensland legislation).

Legislation at State and Territory and Commonwealth levels has ensured consideration of complaints of discrimination in the areas of medical services, employment and prisons (for example, segregation of HIV-positive prisoners in Western Australian prisons).

The May 1995 Justice Statement issued by the Commonwealth Government proposed the establishment of a national Human Rights and Discrimination Law Centre, which has been given additional funding to conduct a review of discrimination against homosexuals, including discrimination in connection with finance and property.

Enactment of the Commonwealth's *Human Rights (Sexual Conduct) Act 1994* effectively decriminalises homosexuality in Tasmania. It also introduces an age of consent of 18 years for all homosexual activity, while preserving lower ages of consent in jurisdictions where this is legal. There is, however, still inconsistency between heterosexual and homosexual ages of consent.

### 8.3.4 Other legal matters

Changes to the regulation of the sex industry have occurred in a number of jurisdictions, but in no case have all the LWP's recommendations in this regard been implemented. The Australian Capital Territory has gone closest to implementing all of them. The New South Wales Premier recently announced his intention to decriminalise and regulate the industry. In some jurisdictions the LWP's recommendations have been implemented only in part (for example, Victoria and the Northern Territory) and in others the legislation has moved in

the opposite direction (for example, Queensland). In South Australia, a private member's Bill to decriminalise and regulate prostitution was defeated by Parliament, although a joint committee of both houses of Parliament is soon to report on the subject. No change has occurred in Tasmania and Western Australia.

Legislative protection of needle and syringe exchanges now exists in all jurisdictions. This is an excellent example of the law reinforcing public health measures.

One of the most difficult legal issues is access to condoms, needles and syringes by prisoners. No progress has been made on the availability of sterile needles and syringes in prisons in any jurisdiction. The Australian Capital Territory is the only jurisdiction that makes condoms available to detainees on remand. In New South Wales, a civil action alleging a breach of the duty of care to prisoners has been rejected on appeal. The New South Wales Government recently gave approval for a trial program of allowing prisoners access to condoms; the trial is a result of a recommendation in the report of the New South Wales Implementation Working Party.

### **8.3.5 Public health legislation and civil liability**

The reform of public health legislation is a matter for State and Territory departments responsible for health. Moves to reform such legislation have been slow, they vary between jurisdictions, and they lack uniformity. Among the subjects to be considered are due process rights, uniform collection of national surveillance data, structured discretions in relation to partner notification and restrictions on living circumstances in exceptional cases, privacy protections, remedies for lack of informed consent, and codification of infection control guidelines. New South Wales, Victoria, South Australia and Tasmania have partially implemented the the LWP's recommendations in this regard. Western Australia, Queensland, the Australian Capital Territory and the Northern Territory have been in the process of reviewing their laws for several years. New South Wales and Tasmania provide positive examples of public health legislation reform by enabling infection control guidelines to be legislatively binding in certain circumstances. Confidentiality provisions have been strengthened under New South Wales public health legislation.

## **8.4 ROLES, RESPONSIBILITIES AND RESOURCES**

Implementation of the National HIV/AIDS Strategy is assisted if HIV/AIDS-related legal matters are dealt with at multiple levels. This includes policy formulation by the bureaucracy, advocacy by the community sector, education for the legal profession and people living with HIV/AIDS, and clinical legal service delivery for individual cases. In these areas Australia is seen by some as an international model. There has been great demand from multilateral organisations, community groups and individuals for access to materials and resources on legal

## THE LAW AND HIV/AIDS

A man whom many believe was forced out of the Australian Parliament by his own political party because of his close association with the gay community now presides over the administration of some of the most progressive gay and HIV/AIDS discrimination laws in the world.

He is former Senator Chris Puplick, now President of the New South Wales Anti-Discrimination Board, whose charter includes laws prohibiting people from discriminating against others on the grounds of their sex, marital status, nationality, homosexuality or their health status (disability), along with very specific anti-discrimination legislation directed to protect the gay community and people infected with HIV/AIDS.

The laws also extend to prevent vilification of gay people and those with HIV/AIDS, making it an offence in New South Wales to vilify such people.

A controversial political figure now in the public service, Chris is still a strong philosophical liberal and recalls proudly the contribution he made in the early days of the HIV/AIDS epidemic to establishing bipartisan support within the Australian Parliament for the coordinated effort to curb the spread of the disease.

'From as early as 1985 I encouraged the Liberal Party to join forces with the Labor Government to help fight this pandemic,' he said.

'In 1985 I made my first speech on HIV/AIDS at a time when I already knew personally one of the first 17 people who had died from the virus. I was instrumental in the formation of the Parliamentary Liaison Group on AIDS, an all-party advisory committee on HIV/AIDS that still exists today, and then I went on to produce a number of significant public reports for both State and Federal governments on various aspects of the issue which helped shape Australia's response to the epidemic.'

Chris is also chairperson of the New South Wales Privacy Committee, a body that has taken a leading role in protecting the rights of people with HIV/AIDS.

In a voluntary capacity, Chris is also the chairperson of the AIDS Trust of Australia, the country's leading national charitable organisation raising funds for HIV/AIDS research, treatment and care, and education.

'This organisation enlists the financial support of the business community and the general public and receives a number of bequeaths. We run the Red Ribbon Appeal on World AIDS Day and our funds rely heavily on charity concerts and high-profile events,' he explained.

'The funds raised are then given as grants to a number of community-based organisations working across the spectrum of HIV/AIDS throughout Australia.'

education, research and law reform initiatives, and in Australia the output of quality legal work on HIV/AIDS-related matters has been high.

Cooperation between the health and law portfolios at the Commonwealth and State and Territory levels continues to be essential. At the Commonwealth level, the Attorney-General's Department has prime responsibility for continuing program development associated with HIV/AIDS legal matters. This is consistent with the trend towards mainstreaming outlined in the Strategy. As with the evaluation's other findings in relation to mainstreaming, clear delineation of roles and responsibilities and a strategic approach are essential to ensure that legal reform and other legal matters are not lost among competing priorities. The Attorney-General's Department has done a large amount of work on HIV/AIDS-related legal questions, but strong arguments have been put that its human and financial resources are inadequate to respond in full.

#### **Recommendation 56**

**It is recommended that the Commonwealth Attorney's-General Department enhance its capacity to respond to legal problems presented by HIV/AIDS.**

### **8.4.1 Legal policy and law reform**

The Implementation Working Group has not been able to deal with the broader range of HIV/AIDS legal problems associated with the National HIV/AIDS Strategy, nor with other legal problems not examined in the LWP report. Some of these may be of great importance in a changing HIV epidemic; for example, Aboriginal and Torres Strait Islander communities' access to justice. There is a continuing need for consideration of the broad social and legal reform questions presented by HIV/AIDS and other communicable diseases. The Implementation Working Group is an appropriate mechanism to do this, but at present it is not adequately resourced.

The NAPWA submission called for 'the creation of true intersectoral (not just Health) structures at both a State and national level to implement ... the unfinished legal reform agenda' (Submission 69). Similarly, AFAO submitted that all jurisdictions should establish committees (with community representation) to formally monitor and review the implementation of legal reform recommendations.

Consideration should be given to examining the existing structures for dealing with HIV/AIDS legal matters at the State and Territory and national levels in a coordinated and multisectoral manner. Roles and responsibilities should be made clear in all jurisdictions, and all States and Territories should be encouraged to establish bodies comparable with the Implementation Working Group.

**Recommendation 57**

**It is recommended that the Commonwealth Attorney-General's Department and the Commonwealth Department of Human Services and Health encourage all jurisdictions to establish bodies to implement the Legal Working Party's recommendations.**

**Recommendation 58**

**It is recommended that the Commonwealth Attorney-General's Department review the effectiveness of the Implementation Working Group and make recommendations on the roles, responsibilities and resourcing of a national, intersectoral body to consider continuing legal reform questions associated with HIV/AIDS and other communicable diseases.**

**8.4.2 Delivery of legal services and education of legal practitioners**

The NAPWA and AFAO submissions provided evidence that existing specialist legal advocacy services have problems meeting the demand by people living with HIV/AIDS for legal services.

One barrier to responding to the needs of the community is the private sector's lack of understanding of the complex issues surrounding HIV/AIDS. Legal practitioners need training and resource material to enable them to deal appropriately with and understand these issues. And private industry should, in part, meet the demand for HIV/AIDS-related legal services and provide advice on legal matters that may be relevant to people living with HIV/AIDS, their families and those involved in caring for them, as well as employers, industry groups, medical practitioners and other lawyers. Additional mechanisms are needed to encourage legal education bodies (for example, continuing legal education and tertiary institutions) to provide HIV/AIDS-related legal education.

There have been number of community-based initiatives. Specialist HIV/AIDS legal centres have been established at the AIDS councils in Sydney and Melbourne. They are based on the community legal centre model and involve large numbers of volunteer lawyers. The New South Wales centre employs one full-time lawyer; the Victorian one is totally run by volunteers. Both services had difficulty attracting funding. The relevant State health departments take the view that it is inappropriate to use the Matched Funding Program to fund legal services, although some temporary funding has been given to the New South Wales centre.

There are many demands on the community legal centre budget administered by the Commonwealth Attorney-General's Department and no specialist HIV/AIDS legal services have been funded. The Department of Human

Services and Health does fund a legal policy officer at AFAO and additional funding from the National Priorities Program has been provided to educate lawyers in community legal centres and private legal practices about HIV/AIDS. Part of the intention of this project is to build capacity within the existing legal framework, so that HIV/AIDS matters become part of lawyers' normal work.

Consultations and submissions suggest that the current system does not adequately meet the demand by people living with HIV/AIDS for legal services. There is a need to enhance the capacity of private industry and community legal centres to meet the demand for HIV/AIDS-related legal services. Means should be developed to facilitate the appropriate mix of specialist and generalist advice available through community legal centres and private legal practices.

#### **Recommendation 59**

**It is recommended that the Implementation Working Group give consideration to measures needed to facilitate the appropriate mix of specialist and generalist advice available through community legal centres and private legal practices.**

## **8.5 DISCRIMINATION**

Consultations and submissions identified continued discrimination against people on the basis of known or imputed HIV status, both in the general community and in health care settings. This includes discrimination against people who are HIV positive, gay men, injecting drug users and sex workers. Education and formal complaints processes have been the two main mechanisms used to confront discrimination and its impact on individuals, carers and partners.

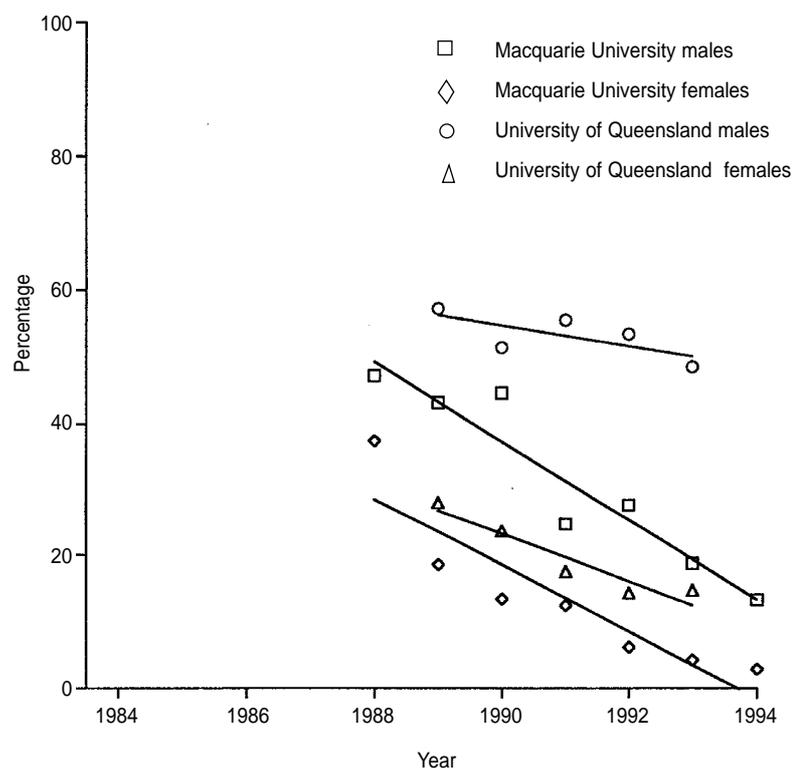
The National Education Program has developed major initiatives in discrimination education, among them a national education campaign—HIV Doesn't Discriminate, People Do—in 1992 and 1994. Discrimination by health care workers was raised as an area of particular concern so pilot projects were conducted by the Program to explore ways of decreasing HIV/AIDS-related discrimination among health care workers and to improve the skills and knowledge of people living with HIV/AIDS to combat discrimination.

Between 1992 and 1994 four quantitative tracking surveys were conducted to monitor changes in knowledge and attitudes related to HIV/AIDS and discrimination in the general community. These surveys found a gradual decrease in discriminatory attitudes towards HIV/AIDS, people living with HIV/AIDS and priority groups, with the exception of injecting drug users. In particular, discriminatory attitudes towards homosexuals have decreased dramatically (Lenahan Lynton Bloom Blaxland 1994). Surveys of university

students in Sydney, Brisbane and Melbourne between 1987 and 1994 show a considerable decrease in the extent to which students say they would avoid social contact with gay men (see Figure 8.1), bisexual men and sex workers. There is, however, no evidence of changed trends over time in social avoidance of injecting drug users (Smith et al. 1995).

Reforms connected with HIV/AIDS- and homophobia-related discrimination are also occurring in schools. For instance, a review of such discrimination was undertaken by the New South Wales Board of Studies, the Department of School Education and the New South Wales Anti-Discrimination Board. The review has resulted in changes in New South Wales school curricula, the

**Figure 8.1 Percentage of 18- and 19-year-olds reporting that they would avoid contact with gay males: selected universities, by sex, 1984 to 1994**



Source: Smith et al. (1995).

development of teaching material concerning such discrimination, and the development of grievance procedures in schools.

Complaints mechanisms now exist at both State and Territory and Commonwealth levels. Complaints under the Commonwealth's *Disability Discrimination Act 1992* are considered by the Human Rights and Equal Opportunity Commission. All States and Territories have, or are in the process of

establishing, some form of human rights tribunals or medical complaints tribunals, or both.

Consultations and submissions supported the existence of formal complaints mechanisms. But many organisations dealing with HIV/AIDS matters noted that there are substantial problems with the capacity of these mechanisms to deal with the number and range of problems that arise and to resolve complaints in a timely fashion. The NAPWA submission identified the need for a mechanism for hastening the consideration of complaints by people with life-threatening illnesses and for undertaking class actions.

Consultations and submissions also suggested that the extent of discrimination against people living with HIV/AIDS has diminished since the early days of the epidemic, although areas having a low prevalence of HIV/AIDS are often identified as those in which discrimination and breaches of confidentiality, by health care workers and the general community, continue in the most obvious forms. AFAO and NAPWA submitted that considerable problems still exist. Discrimination against injecting drug users and Aboriginal and Torres Strait Islander people was noted during consultations.

#### **Recommendation 60**

**It is recommended that anti-discrimination education for the general community and health care workers remain a priority for education and prevention.**

#### **Recommendation 61**

**It is recommended that the Human Rights and Equal Opportunity Commission and State and Territory bodies that deal with formal discrimination complaints improve their mechanisms for hastening the consideration of complaints by people with life-threatening illnesses and for undertaking class actions.**

# Roles and responsibilities in the partnership

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Chapter 2 describes the organisational infrastructure for the National HIV/AIDS Strategy. This chapter reviews the roles and responsibilities of those involved in the partnership and discusses how these might be developed to consolidate achievements and respond to future challenges.

## 9.1 THE PARTNERSHIP

The second Strategy says,

At the core of Australia's approach to HIV/AIDS has been an effective partnership between:

- governments at all levels;
- medical, scientific and health care professionals; and
- affected communities. (Commonwealth of Australia 1993a, p. 2)

The concept of partnership involves a commitment from all parties to work together as equals to solve the problems created by HIV/AIDS. It has meant empowering those who are most affected by the epidemic and drawing on a broad range of expertise both within and outside government. It implies recognition and respect for the different roles and responsibilities of the various members. There is no single organisational expression of the



partnership; rather, it is an organising principle commonly used when policies, processes and structures are being developed.

Varying opinions of the partnership were expressed during consultations and in a number of submissions. Some see the partnership as the striking achievement of the Australian response to HIV/AIDS; others expressed frustration that it did not live up to its goal of involving all affected communities equally. Despite widely acknowledged tensions in the partnership, there was a general view that it had worked well in advancing the struggle against HIV/AIDS. There was consensus on the need to maintain and foster the partnership in a third Strategy.

### **Recommendation 62**

**It is recommended that a third National HIV/AIDS Strategy endorse the continuing need for a partnership approach to the epidemic.**

There has been no consistency in the way Aboriginal and Torres Strait Islander people have been included in the partnership by Commonwealth, State and Territory governments, the community sector, researchers and health professionals. The heterogeneity and geographical dispersion of Australia's indigenous people have inhibited progress in establishing their full and equal participation in the Strategy with the Commonwealth, the State and Territory governments, and non-indigenous representative bodies.

One positive development during 1995 was the proposal by ANCA to establish an ANCA Working Party on Aboriginal and Torres Strait Islander Sexual Health. ANCA also hosted a forum for Aboriginal and Torres Strait Islander sexual health workers in Alice Springs, which nominated individuals to sit on the Working Party. The Working Party is being developed and is planned to have majority membership of Aboriginal and Torres Strait Islander people, plus experts in HIV and sexual health. This is an important step towards a partnership with Aboriginal and Torres Strait Islander people at the national level of HIV/AIDS/STD policy making. It should be given maximum support by the Commonwealth.

Elsewhere in this report it is stressed that efforts by State and Territory governments to improve indigenous people's sexual health should be increased. The major mechanism at the Commonwealth level for facilitating and resourcing this is the Special Funding Program, which has guidelines requiring State and Territory governments to consult Aboriginal and Torres Strait Islander communities. The Matched Funding Program has historically been an important mechanism for funding HIV/AIDS projects for indigenous people. The existing consultation arrangements have not sufficiently enhanced Aboriginal and Torres Strait Islander ownership of sexual health and HIV prevention policy. The Commonwealth should review the Special Funding Program guidelines with a view to strengthening requirements in this regard.

HIV/AIDS/STDs is only one of the health care concerns of Aboriginal and Torres Strait Islander people. Policy development, planning and consultation mechanisms in this regard need to dovetail with broader initiatives at the Commonwealth level through the Office for Aboriginal and Torres Strait Islander Health Services.

**Recommendation 63**

**It is recommended that the Commonwealth give maximum support to the development of a partnership with Australia's indigenous people through the Australian National Council on AIDS Working Party on Aboriginal and Torres Strait Islander Sexual Health.**

**Recommendation 64**

**It is recommended that the Commonwealth strengthen its requirement that State and Territory governments develop strategic plans for the use of Special Funding Program funds in partnership with Aboriginal and Torres Strait Islander people. The Commonwealth should ensure adequate links with broader participation mechanisms established through the Office for Aboriginal and Torres Strait Islander Health Services.**

## **9.2 THE COMMONWEALTH GOVERNMENT**

The second National HIV/AIDS Strategy says the Commonwealth's role is to provide leadership on matters of national significance, to manage public education programs and the national HIV/AIDS Research Program, and to coordinate and monitor the Strategy at a national level.

It is appropriate under Australia's federal system that the State and Territory governments administer services at a local level: they have both legislative power and functional responsibility for the range of services that are connected with public health. But there is great diversity between jurisdictions. Their epidemics are different, their service delivery infrastructures are different, and their legislative environments are different. This reinforces the need for Commonwealth leadership to ensure a synergistic, efficient and effective national response. The Commonwealth should, however, continually focus its attention on the areas where it is most useful in responding to HIV/AIDS. This will most probably lead it towards strengthening its capacity to monitor the epidemic and the adequacy of the national response. Related to these are the roles of leadership, planning and coordination.

During the second Strategy, and in keeping with the recommendations of the 1992 evaluation, the Commonwealth has started to withdraw from direct service provision. This should continue to occur as the Commonwealth's more strategic role develops. The second Strategy delineated roles and responsibilities to ensure improved coordination and planning but further work is necessary. The Commonwealth is in an excellent position to facilitate this.

Accountability and monitoring mechanisms were built into the first and second Strategies but in many instances they could be more effective. Outcome measures and performance indicators should be part of program development and should be used to monitor a third Strategy. The Commonwealth should work with other members of the partnership to improve capacity in this area.

**Recommendation 65**

**It is recommended the Commonwealth continue to move away from direct service delivery and assume a stronger role in strategic planning, coordination, leadership and monitoring of outcomes achieved through the Strategy.**

### **9.3 THE STATE AND TERRITORY GOVERNMENTS**

The second Strategy says the State and Territory governments are responsible for providing leadership at the level of their jurisdiction. They are also responsible for program administration and coordination of service delivery within their jurisdictions.

To manage their programs effectively, the States and Territories need to optimise their planning and administrative arrangements. Funding patterns must be flexible and responsive to local needs, rather than follow historic funding patterns. Consideration should be given to the problem of resources being fragmented across many small projects, rather than being allocated in a planned way and in keeping with clearly identified priorities. There need to be adequate monitoring and accountability measures to ensure appropriate use of program funds. The States and Territories and the Commonwealth need to cooperate to ensure alignment of performance measures. Further, the States and Territories must closely liaise with each other and the Commonwealth via the IGCA to maximise national coordination and planning.

A proportion of State and Territory programs are delivered by community-based organisations. In many instances the main organisation is an AIDS council. A number of submissions suggested that AIDS councils have become heavily bureaucratised and are no longer responsive to the needs of their constituencies. This was of particular concern to NAPWA, which said that in some jurisdictions AIDS councils tended to view people living with HIV/AIDS as clients rather than partners who should have an important role in service delivery.

It is the responsibility of the States and Territories to ensure that the community-based organisations they fund have adequate links with their constituents and are the most appropriate organisations to deliver specific services. This is of particular relevance in the case of AIDS councils, given their historically high levels of funding.

**Recommendation 66**

**It is recommended that State and Territory governments continue to have prime responsibility for program administration and coordination of service delivery within their jurisdictions. They should ensure that services are responsive to local needs.**

**Recommendation 67**

**It is recommended that State and Territory governments ensure that community-based organisations they fund have adequate links with priority groups, are responsive to their clients, and are the most appropriate organisations to deliver specific services.**

## **9.4 THE INTERGOVERNMENTAL COMMITTEE ON AIDS**

As a standing committee of the Australian Health Ministers Advisory Council, the IGCA is an essential forum for the coordination and planning of Commonwealth and State and Territory activity in Australia's federal system of government. It continues to be the most appropriate forum for the development of program monitoring tools and its work in this area should be a priority.

Although the second Strategy established broad priorities, the current infrastructure has not worked effectively in coordinating a strategic response. Some parts of some programs have plans and planning mechanisms, but coordination to ensure adequate linking of the four programs and of elements within the four programs appears to have been ineffective. The effectiveness of the Commonwealth role in ensuring that this occurs must be questioned, as should the role of the ANCA, IGCA and AFAO education sub-committees in planning.

A single, national education sub-committee, formed under the auspices of ANCA and with representation from all relevant organisations, would facilitate coordination and planning of education and prevention programs.

As mainstreaming is consolidated during a third Strategy, the role of the IGCA and its relationship with associated Commonwealth, State and Territory forums in other areas of communicable diseases should be reviewed; consideration should be given to the amalgamation of some of these bodies.

**Recommendation 68**

**It is recommended that the Intergovernmental Committee on AIDS coordinate the development of performance measures, including outcome indicators and program monitoring tools, as a priority.**

**Recommendation 69**

**It is recommended that a single, national education sub-committee of the Australian National Council on AIDS be formed for strategic planning and coordination of education and prevention programs. This sub-committee should have representation from all relevant organisations.**

**Recommendation 70**

**It is recommended that during a third Strategy the Commonwealth and the States and Territories review the role of Intergovernmental Committee on AIDS and its relationship with other national communicable diseases committees. It should be reconstituted as a body with broader terms of reference and broader representation as appropriate.**

## **9.5 THE AUSTRALIAN NATIONAL COUNCIL ON AIDS**

The second Strategy says that ANCA is the Commonwealth Government's key advisory body on HIV/AIDS and should principally be concerned with identifying national needs, objectives and priorities and providing information to the public.

Because HIV/AIDS is connected with other health and societal issues, ANCA has been increasingly active in areas that have much broader relevance; for example, work on infection control guidelines, the sexual health of Aboriginal and Torres Strait Islander people, and legal and ethical questions. ANCA's terms of reference should be revised to ensure that it has a clear mandate for dealing with matters that are wider than HIV/AIDS but that must be dealt with by a body such as ANCA in order to ensure an effective response to HIV/AIDS. ANCA should also have greater scope to make use of (either permanently or as required) expertise from beyond the field of HIV. ANCA may be required to collaborate with or assist other bodies where it is more appropriate that these other bodies take primary carriage of some matters.

The integration of ANCA within the NHMRC structure of expert advisory committees has been mooted for some time (Commonwealth of Australia 1993b). The time is not right for this to happen. The recent review of the NHMRC said that it should move towards being more relevant and responsive to the Commonwealth's role in managing public health, but this has not happened to the extent that HIV/AIDS could be incorporated within its structure without significant loss to the Commonwealth's capacity to respond effectively.

HIV/AIDS is still exceptional within the public health sphere because it has a unique combination of characteristics: it is 100 per cent fatal (as far as we know); there is a long incubation period during which an HIV-positive person may be unaware of his or her infection or may have to sustain safe sexual

## HELPING TO SHAPE THE COURSE OF HIV/AIDS

The Australian National Council on AIDS has been at the forefront of the fight against HIV/AIDS in Australia, acting as an independent advisory body to various federal Ministers for Health.

Fearlessly and without political favour, it has taken on issues of new treatments, research and surveillance, the rights of people living with HIV/AIDS, infection control in medical settings, sexually transmissible diseases in indigenous Australian communities, and the direction of education and information at a national level. Made up of individual experts, from doctors to social researchers, from HIV-positive people to lawyers and indigenous Australians, ANCA has been a persuasive influence on how Australia has responded to HIV/AIDS.

Chairperson for a second time is Dr Don Grimes, a former Minister in the Hawke Government of the early 1980s, when the HIV/AIDS epidemic was first identified in Australia. As the only doctor in the Cabinet at the time and as representative in the Senate for Health, Don became immediately involved in the issue and as Minister for Community Services made money available from his budget to develop a range of programs to alert the Australian people to the epidemic.

As he moved on in life Don continued his interest in HIV/AIDS, representing Australia at the WHO Conference on AIDS in Prisons in 1987 and then later, as Australian Ambassador to the Netherlands, he kept a close eye on the revolutionary reforms and education initiatives undertaken by the Dutch Government to control HIV/AIDS. In 1992 he was appointed to the Chair of ANCA; he was re-appointed in 1995.

Don believes that ANCA still has a very important role to play because of its ability to co-opt experts in various fields as needs be and to work in a non-political, bipartisan way. 'Keeping politics out of AIDS has been very beneficial for Australia's containment of the disease,' Don said.

On the achievements of Australia in HIV/AIDS, Don cites the confinement of the disease to the place where it began—the gay community—and reducing the number of cases considerably in that group and introducing policies that are non-discriminatory and preserve individual freedom. 'Involving the affected community itself in creating policies and keeping partisan policies by and large out of the debate have also been great achievements,' he said.

On HIV/AIDS into the next decade, Don believes the biggest challenges are to further decrease the new infection rates, particularly in young gay men, and to prevent any widespread outbreak of HIV in Aboriginal and Torres Strait Islander communities, which he strongly asserts not only involves AIDS policy but health policy in general.

In line with his concerns for indigenous Australians, the ANCA, under Don's guidance, has embarked on a wide-ranging investigation of the causes and effects of HIV/AIDS and other STDs in Aboriginal and Torres Strait Islander communities. It is developing a national strategy to deal with the crisis and will report to government later this year.

and/or injecting practices; there is no cure; and the major modes of transmission involve intimate and sometimes illegal behaviour, making prevention efforts difficult. In addition, Australia is part of a region with rapidly growing HIV epidemics.

Although Australia has been successful in controlling the epidemic in a number of areas, there is still cause for concern. The Commonwealth Minister for Health and the Department of Human Services and Health continue to require expert, independent advice from a body that has the capacity to respond quickly to problems as they emerge and also takes account of the viewpoints of a range of experts and the affected communities.

#### **Recommendation 71**

**It is recommended that the role of the Australian National Council on AIDS be endorsed and strengthened in a third Strategy. The Council should be given a mandate to deal with a broader range of matters of relevance to HIV/AIDS and to collaborate with other bodies as appropriate.**

## **9.6 THE AUSTRALIAN FEDERATION OF AIDS ORGANISATIONS**

AFAO is the organisation that represents State and Territory AIDS councils, NAPWA, the Australian Intravenous League and the Scarlet Alliance. The second Strategy says AFAO has a central role to play through maintaining effective participation in the Strategy by communities most affected by HIV, by coordinating the efforts of community-based organisations, by facilitating information exchange, and by contributing to the development of national policies, programs and strategies.

AFAO has received umbrella status funding from the Community Organisation Support Program—an unusual arrangement as umbrella status funding is not usually accorded to disease-specific groups. It has also received funding from AusAID.

In terms of HIV/AIDS-specific funding, during the second Strategy the Commonwealth has funded AFAO for a program of activities negotiated annually with the AIDS/Communicable Diseases Branch. The Commonwealth has also provided National Education Program and the National Priorities Program funds to AFAO for specific projects: in 1993–94 these totalled over \$1 million. The recent review of national gay education infrastructure concluded that AFAO may be the appropriate organisation to coordinate national gay education, a move that would entail some reallocation of resources within AFAO.

The Commonwealth should work with AFAO to develop a set of outcomes and associated performance indicators, which should be the basis of an annual

funding agreement. This would allow AFAO greater flexibility in internal administration and would give the Commonwealth greater ability to ensure that funds were being spent effectively.

NAPWA made strong representations to the evaluation that it be funded independently from AFAO. NAPWA's desire for independence is acknowledged, but it would not be advantageous to fund a parallel advocacy organisation, nor would an argument to do so be sustainable at the Commonwealth level. It is the responsibility of AFAO to develop effective and efficient organisational arrangements that allow for appropriate input from its broad constituency. Central to these arrangements should be an acknowledgment of the contribution of people living with HIV/AIDS.

**Recommendation 72**

**It is recommended that the Commonwealth fund the Australian Federation of AIDS Organisations on the basis of an agreed set of outcomes and an agreed set of performance indicators to monitor those outcomes.**

## **9.7 HAEMOPHILIA FOUNDATION AUSTRALIA**

The second Strategy says that Haemophilia Foundation Australia's role is to contribute to the development of national policies, programs and strategies and to provide leadership and support for haemophiliacs.

Haemophilia Foundation Australia is funded under the Community Organisation Support Program and has specific-project funding from the Strategy. Continued funding of the Foundation is warranted since people with haemophilia increasingly face the threat of other blood-borne pathogens as well as the long-term challenge of HIV. Funding through a third Strategy should be on the basis of agreed outcomes.

**Recommendation 73**

**It is recommended that Commonwealth funding of Haemophilia Foundation Australia be conditional on an agreed set of outcomes and an agreed set of performance indicators to monitor those outcomes.**

## **9.8 THE PARLIAMENTARY LIAISON GROUP**

The second Strategy says that the role of the Parliamentary Liaison Group is to ensure that members of the Commonwealth Parliament are informed about the latest HIV-related developments and to provide a non-partisan forum for policy discussion. Concerns were expressed during the evaluation about how infrequently the Parliamentary Liaison Group has met during the second Strategy.

The Parliamentary Liaison Group remains an important vehicle for creating and maintaining a non-partisan approach to HIV/AIDS. A major achievement of Australia's response has been the development of consensus on managing HIV/AIDS. Every effort needs to be made to ensure continued non-partisan political support. The Commonwealth should ensure that the Parliamentary Liaison Group continues and is adequately supported.

Parliamentarians also need a vehicle to receive briefings on other public health problems such as hepatitis C. The establishment of a separate liaison structure with this larger role would not be cost-effective; the Parliamentary Liaison Group should be given the opportunity to receive briefings on a range of diseases or important public health concerns.

To ensure that members of parliament across the political spectrum and in all jurisdictions have the opportunity to be briefed on and discuss public health matters such as HIV/AIDS and hepatitis C, parliamentary liaison groups should be formed at the State and Territory level.

**Recommendation 74**

**It is recommended that the Commonwealth ensure that the Parliamentary Liaison Group continues and is adequately supported. Further, use of the Parliamentary Liaison Group as a vehicle for disseminating information on hepatitis C and other public health problems should be explored.**

**Recommendation 75**

**It is recommended that the Intergovernmental Committee on AIDS and the Australian Health Ministers Advisory Council propose to the Australian Health Ministers Council that parliamentary liaison groups be established at the State and Territory level as part of the continuing development of a non-partisan approach to HIV/AIDS and other public health matters.**

## Financing and accountability

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This chapter presents conclusions resulting from the examination of funding and accountability arrangements for the second National HIV/AIDS Strategy.

### 10.1 PRESSURES FOR CHANGE

The question of whether the National HIV/AIDS Strategy should continue must be considered in light of current directions in the reform of health and community services, which are being proposed by the Council of Australian Governments. The proposed reform has two objectives. The first is to better accommodate people's needs by providing more choice in the range of services available, better information about the services that are available, and better continuity and coordination of care. The second objective is to promote government planning that will lead to investment in early intervention and preventive services, planning and management of services as close as possible to the level of service delivery, and incentives for best practice (Council of Australian Governments 1995).

There is broad agreement that the plethora of special-purpose programs through which the Commonwealth provides funds to State and Territory governments for specific activities in areas such as HIV/AIDS should be reduced. The Department of Human Services and Health administers over 40 of these special-purpose programs—the Matched Funding Program and the Medicare agreements are just two. The current arrangements are thought to be inefficient and to lead to continuing friction between the Commonwealth and the States and Territories over matters relating to accountability and responsibility while little attention is paid to looking at the health and community services system from the perspective of the people for whom it is intended. There is general agreement that accountability mechanisms should move towards ensuring that people's needs are being met and that programs are fulfilling their stated objectives, through greater use of measures of program outputs and outcomes and less emphasis on input controls.

In connection with the National HIV/AIDS Strategy, two questions for the Commonwealth emerge from this reform process. First, does the Commonwealth still need a specific-purpose program for HIV/AIDS or can State and Territory governments be left to manage the epidemic and its consequences without earmarked Commonwealth funds and direct Commonwealth involvement? If the answer to the first part of this question is

'yes', then how can accountability be improved through the greater use of measures of program outcomes and outputs? Consequent to these questions are the perennial questions relating to fiscal responsibility—is the present level of financing through the Strategy adequate, too large or too small? and is the distribution of funds between the different programs right or should it be adjusted to reflect new priorities?

## 10.2 THE NEED FOR A THIRD STRATEGY

The continuing need for each of the Strategy's four programs is discussed in some detail in Chapters 4 to 7. The Strategy's additional elements—national goals, principles, agreed roles and responsibilities—provide an overarching policy framework that facilitates the effective implementation of these programs.

The continuing unsatisfactorily high plateau of infections among homosexually active men, the emerging epidemic among Aboriginal and Torres Strait Islander people, and the growing epidemics in the Asia-Pacific region, all point to the need for continuing a national strategic approach to HIV/AIDS in a third Strategy. HIV/AIDS remains a sufficiently large and unique problem to warrant special treatment. Much progress has been made to integrate the response to HIV/AIDS into the response to related problems in the area of sexual health and communicable diseases; this should continue. By the end of a third Strategy, the need for a National HIV/AIDS Strategy may be made redundant by advances in the development of national policy frameworks in these related areas. This course of action should be consciously pursued during a third Strategy.

A third Strategy should, however, not be confined to a three-year horizon. The problems created by HIV/AIDS and their potential to become uncontrollable will not go away in the short term and another major evaluation within three years would be disruptive to the work that needs to be done. The next Strategy should have a five-year time frame, with a monitoring framework that focusses as much as possible on program outcomes and outputs.

Mainstreaming of HIV/AIDS activities is discussed in many places in this report, especially Chapters 4, 5 and 6. At the Commonwealth level this should be pursued through a strategic reform process that aims to make the need for a separate and disease-specific HIV/AIDS policy framework redundant. During the period of a third Strategy the Commonwealth should develop a national communicable diseases and/or sexual health policy framework that is sufficiently robust to deal with HIV/AIDS but integrates the response to HIV/AIDS with that required for other related problems. This move would be consistent with the larger reform process of moving towards fewer specific-purpose programs.

**Recommendation 76**

**It is recommended that the Commonwealth, in consultation with all other members of the partnership, develop a third National HIV/AIDS Strategy, which should have a mandate until 2000–01.**

**Recommendation 77**

**It is recommended during the proposed third National HIV/AIDS Strategy the Commonwealth develop a national policy framework that integrates the essential elements of a successful response to HIV/AIDS with those required for managing problems in the areas of sexual health and communicable diseases.**

**10.3 FUNDING ARRANGEMENTS**

The Strategy provides funds for wholly Commonwealth funded and managed programs and for programs for which the Commonwealth and the States and Territories have shared responsibility.

**10.3.1 Commonwealth programs**

The second Strategy recognises six areas of Commonwealth involvement: the National Education Program, the National Priorities Program, the national evaluation program, the Research Program, support for national community-based organisations, and support for national HIV/AIDS committees.

**The National Education Program**

There has been criticism that the NEP lacks strategic direction, has failed to link with State and Territory programs, and has not funded projects for priority groups.

The NEP is the main mechanism for general community and professional education at the national level; it provides information about high-risk practices and develops projects designed to sustain a supportive environment for HIV/AIDS activities. Its role in national leadership and coordination should be reaffirmed, although it is important that this role does not compromise projects for priority groups.

In keeping with other recommendations that the Commonwealth move away from direct program development, funding for the NEP should be reviewed when a third HIV/AIDS Strategy is being formulated. The Program should continue, but on a smaller scale and with a focus on major projects that require a national approach (such as national media strategies) and projects that coordinate with State- and Territory-based initiatives. It should have clearer guidelines that are linked to appropriate monitoring and transparent strategic planning mechanisms. The possibility of linking NEP activities with other

Commonwealth initiatives in the area of sexual health should also be explored in a third Strategy.

### **The National Priorities Program**

There has been criticism that the NPP lacked a clear strategic direction in the first half of the current Strategy and that there has been confusion in the community about its role. The Program has fulfilled its mandate by funding a number of initiatives in response to emerging challenges and gaps in current programs. It should not be used to provide services or deal with problems that are well within the domain of other programs. Its role should be to respond to problems that require national leadership and coordination and are outside the scope of other programs.

The NPP should continue, with a similar level of funding but with clearer guidelines that are linked to appropriate monitoring and transparent strategic planning mechanisms. Because its role is to provide the Commonwealth with the capacity to respond to emerging problems and problems requiring urgent attention and because it is possible that these will arise unpredictably, efficient management of NPP resources may lead to underspending in some years. This should be allowed to happen without financial penalty to the Program.

### **The national evaluation program**

This evaluation is the second comprehensive national evaluation of the National HIV/AIDS Strategy. Such evaluations are an important source of information for policy development and they are also a catalyst for critical reassessments of policy and practice. It seems sensible, however, that another large, comprehensive evaluation not be undertaken until the end of a third Strategy. If the third Strategy is a five-year strategy, as is strongly recommended, the next comprehensive evaluation would report in the second half of the year 2000. The evaluation agenda between now and then should concentrate on the development of more effective performance monitoring tools and on the further development of social, behavioural and epidemiological methods for assessing the final outcomes of the Strategy, including periodic national surveys. Funding of the national evaluation program should continue at its current level so that this can happen.

### **The Research Program**

Over 50 per cent of Research Program funds are devoted to the three National Centres in HIV Research, which have funding agreements until 1998. The National Centre in HIV Social Research, the National Centre in HIV Epidemiology and Clinical Research, and the National HIV Reference Laboratory are critical to the capacity of Commonwealth, State and Territory governments to manage the HIV/AIDS epidemic. The Commonwealth's administration of them should reflect this core function and should lie within

the AIDS/Communicable Diseases Branch of the Department of Human Services and Health. The capacity to respond to emerging problems with appropriate research should also be built into the funds available to the AIDS/Communicable Diseases Branch.

As discussed in Chapter 6, provided suitable ‘ring-fencing’ arrangements can be made for project grants and training awards, their inclusion in the NHMRC funding base is appropriate.

### **Support for national community-based organisations**

Funding for AFAO and Haemophilia Foundation Australia should continue on the basis of an agreed set of outcomes related to the objectives of a third Strategy to be achieved within an annual grant period, as recommended in Chapter 9.

### **Support for national HIV/AIDS committees**

ANCA, the IGCA, and the Parliamentary Liaison Group are all supported in a minor way with program funds. They also receive a considerable amount of secretariat support from the AIDS/Communicable Diseases Branch. If these organisations proceed along the lines recommended in Chapter 9, their level of resourcing should be maintained.

## **10.3.2 Commonwealth–State and Territory programs**

There are three programs whereby the Commonwealth provides funds to State and Territory governments: the Matched Funding Program, the Special Funding Program and the Medicare Hospital Funding Grants for AIDS.

### **The Matched Funding Program**

The MFP is central to the cooperative, national response to HIV/AIDS intended by the Strategy and should be continued in a third Strategy.

Strong representations were made during the evaluation for an increase in the total amount of funds to meet new or unmet needs. This is not a realistic proposition in the current fiscal climate, at either the Commonwealth or the State and Territory level, and these needs should be met by reviewing priorities and seeking out efficiencies in existing projects. Nor is there any justification for a decrease in MFP funding: the total number of people living with HIV/AIDS is only just reaching a plateau. The demand for resources for treatment and care services will probably continue to grow at the same time that renewed efforts are needed in some areas of education and prevention.

Some education and prevention funds under the MFP should be reallocated from general community education towards the groups with highest priority—homosexually active men and Aboriginal and Torres Strait Islander people—as discussed in Chapter 4.

Chapter 5 discusses in detail the available options for funding the Treatment and Care Program.

### **The Special Funding Program**

The level of funds provided to the States and Territories under the SFP should be increased to facilitate greater effort in HIV/AIDS/STD education and prevention, greater medical preparedness among health services for Aboriginal and Torres Strait Islander communities, and increased acceptance of and support for HIV-positive indigenous Australians across all health services and in their own communities. There were problems with the first year of implementation of the SFP but these are being remedied and planning is under way in most jurisdictions. Continuing challenges to effective implementation are the inadequacy of the health infrastructure in rural and remote areas and the high cost of providing services in these areas.

The SFP guidelines should be revised to include stronger requirements that the States and Territories develop strategic plans and effective partnerships with Aboriginal and Torres Strait Islander people. The development of better social, behavioural and epidemiological data is critical to the successful management of HIV/AIDS/STDs among indigenous communities. Liaison at the Commonwealth level with the Office for Aboriginal and Torres Strait Islander Health Services should continue, and it may be appropriate at some stage in a third Strategy for the SFP to be integrated with programs in that area.

### **Medicare Hospital Funding Grants for AIDS**

Chapter 5 provides a detailed discussion of and recommendations on the Medicare HFGs for AIDS. If the recommendation to incorporate these funds in general Medicare agreement funds (once adequate compensation can be found for the uneven spread of AIDS cases across the States and Territories) is adopted, consideration should be given to retaining a proportion of these funds (say, 20 per cent) for use in the Matched Funding Program to supplement community care services. This may be particularly useful in the event of a growing number of AIDS cases among Aboriginal and Torres Strait Islander people and the need to supplement funds available for care in rural and remote regions.

### **10.3.3 Conclusions**

Overall, the level of funding for the second Strategy has been adequate and a similar level of funding would be appropriate in a third Strategy. Although this report identifies a number of new problems and unmet needs, better planning and management of existing resources to achieve greater efficiency is the most appropriate course of action.

Some reallocation of funds between programs would be necessary in a third Strategy. The National Education Program should be reduced in size and the



funds used to boost HIV/AIDS and STD work with Aboriginal and Torres Strait Islander people. A reallocation in the order of \$2 to \$2.5 million would leave sufficient funds for the Program to undertake high-priority work while almost doubling the funds available through the SFP.

Whether these funds are used to boost the MFP or the SFP or both needs exploration through the IGCA. The best option appears to be an increase the size of the SFP since these funds are distributed wholly on the basis of the number of Aboriginal and Torres Strait Islander people in each State and Territory. But this should be done only on the basis of stronger guidelines that set out performance criteria and standards for evaluating program implementation.

If the funds were put into the MFP, the States and Territories should be required to quarantine an increased proportion of the MFP for services to Aboriginal and Torres Strait Islander people. The advantage of placing the funds in the MFP is that the matching requirement gives State and Territory governments an additional incentive to see the funds used in an efficient manner. Some States and Territories may not, however, be willing to increase their contribution to match the extra Commonwealth funds.

#### **Recommendation 78**

**It is recommended that the level of funding in a third Strategy be similar to that in the second Strategy and that funds in the order of \$2 million to \$2.5 million be reallocated from the National Education Program to the Special Funding Program for HIV/AIDS and STD services to Aboriginal and Torres Strait Islander people.**

## 10.4 ACCOUNTABILITY

During consultations and in submissions concern was expressed about State and Territory governments, or the organisations they fund (for instance, hospitals), allocating HIV/AIDS funds to non-HIV/AIDS purposes. There was also criticism that the Commonwealth did not adequately monitor the use of funds and did not impose penalties when misallocation occurred.

It is possible that some misallocation of funds does occur. As stated in Chapter 5, the Commonwealth does not require detailed reporting on the use of Medicare HFGs for AIDS. But these funds are only a contribution to the inpatient cost of treating AIDS, so the extent to which they could be used in other areas is very limited. If the funds are being used to treat people living with HIV/AIDS in ambulatory care settings, it is difficult to see what objection could be raised because this is the Commonwealth's preferred mode of treatment wherever possible.

MFP and SFP funds are accounted for by acquittals from State and Territory governments. The details of these acquittals were not reviewed for this evaluation. Both types of funds are reported in some detail in the project register returns. The annual report of HIV/AIDS activities published by the Commonwealth shows that the States and Territories more than match the Commonwealth funds provided under the MFP. Some project returns confuse Medicare HFGs for AIDS with MFP funds, so at least some of this 'additional expenditure' by the States and Territories is actually Commonwealth money. Reporting requirements for a third Strategy should ensure that this confusion stops.

For the MFP, the Commonwealth agrees to broad budget outlines from each State and Territory before each financial year and then collects and analyses project register returns sent in after the end of the financial year. The returns are analysed in terms of broad expenditure categories and priority groups. The same process applies to the SFP, except that projects are approved individually by the Commonwealth Minister before they commence. The practice of seeking ministerial approval for each individual project should be reviewed with a view to delegating this responsibility to an appropriate level in the Department of Human Services and Health.

The project register has a number of deficiencies that limit the effectiveness of monitoring the expenditure of MFP and SFP funds. For instance, there is a gap of two years between the time that the Commonwealth agrees to the State and Territory broad budget outlines and the time that the data from the project register are available for analysis. It is also a difficult area of data collection since many services have multiple target groups and provide a range of services that span education and prevention as well as treatment and care activities. Many services are tailored to local needs and circumstances, which makes it difficult to create discrete categories for data collection.

It would be possible to develop more detailed accounting procedures but these would impose further burdens on the Commonwealth, the States and Territories, and the service providers who supply data. And resources allocated to closer financial administration would not be available for other purposes. Such a course of action would be justified only if there were serious concerns about the misallocation of funds and this is not the case. As noted in Section 10.1, these types of accountability problems are not unique to HIV/AIDS, and the direction of policy reform in this area is to achieve better measures of outputs and outcomes rather than to pursue State and Territory governments in ever tightening circles over the use of program-specific funds.

The project register should be reviewed by the Commonwealth, in consultation with the States and Territories, with a view to streamlining and improving data collection for a third Strategy. The review should encompass the need for program monitoring and accountability to move towards output- and outcome-based systems. Better methods for monitoring activity and outcomes in relation to identified priority services and groups should also be part of the review.

Over 70 performance indicators were developed during the last national evaluation and are still in the developmental stage. They should be reviewed as part of the development of program monitoring tools for a third Strategy.

It must be remembered that the more successfully HIV/AIDS programs integrate with related areas of service delivery the more difficult it is to have HIV/AIDS-specific program monitoring and accountability tools.

#### **Recommendation 79**

**It is recommended that the Commonwealth, in consultation with the States and Territories, review monitoring and accountability mechanisms for a third Strategy, with a view to developing better measures of outputs and outcomes.**

## The method of evaluation

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The evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96 was guided by a comprehensive evaluation framework. The framework set out the terms of reference, proposed a management structure for the evaluation, posed key questions, and described the methodology. It was developed by the AIDS/Communicable Diseases Branch of the Department of Human Services and Health in consultation with an evaluation sub-committee appointed by the Intergovernmental Committee on AIDS. It will be published separately as a technical appendix to the evaluation.

### A.1 EVALUATION QUESTIONS

The evaluation questions were derived by applying each term of reference to the Strategy as a whole and to each of its programs. Among the criteria used to evaluate the Strategy were the following: the incidence and prevalence of HIV/AIDS; the quality and accessibility of services provided to people living with HIV/AIDS; changes in risk practices; how well services and programs deal with the needs, problems and challenges created by HIV/AIDS; and the adequacy and appropriateness of organisational and financing arrangements. The evaluation framework provides a full list of these evaluation questions.

### A.2 DATA COLLECTION AND ANALYSIS

The evaluation questions were examined through collection of both qualitative and quantitative data. Three broad streams of evaluation activity occurred: commissioned analyses in economics, epidemiology, and social and behavioural research; wide-ranging community consultation; and analysis of administrative data.

#### A.2.1 Commissioned analyses

Research was commissioned in 1994–95 to provide data and analysis for the evaluation in the areas of epidemiology, social and behavioural research, and economic analysis. The results of this research will be published separately as technical appendixes to the evaluation report.

The National Centre in HIV Epidemiology and Clinical Research provided a comprehensive picture of HIV/AIDS in Australia (NCHECR 1995). The Centre was funded by the evaluation to conduct a number of additional analyses: HIV testing patterns in the Australian Capital Territory; the

occurrence of AIDS-defining illnesses at Fairfield, St Vincent's and Royal Perth Hospitals; HIV incidence in a cohort of injecting drug users and reconstruction of the incidence of hepatitis B and C among injecting drug users in Australia in the 1980s; HIV seroprevalence among people attending needle and syringe exchanges; and entry and provision of Kirketon Road Centre data.

The social and behavioural research commissioned was as follows:

- an analysis of trends over time in social and behavioural factors relating to the transmission of HIV among injecting drug users and prison inmates, by Nick Crofts, Julie Webb-Pullman (Macfarlane Burnet Centre for Medical Research) and Kate Dolan (National Drug and Alcohol Research Centre) (Crofts et al. 1995);
- an analysis of trends over time in social and behavioural factors related to the transmission of HIV in men who have sex with men, by June Crawford, Suzanne Bermingham and Susan Kippax (National Centre in HIV Social Research, Macquarie University) (Crawford et al. 1995);
- an analysis of trends over time in social and behavioural factors relating to the transmission of HIV among the general community, sex workers and sex travellers, by Anthony Smith, Heidi Reichler and Doreen Rosenthal (Centre for the Study of Sexually Transmissible Diseases LaTrobe University) (Smith et al. 1995).

The commissioned economic research was coordinated by Susan Hurley (University of Melbourne) and Jim Butler (National Centre for Epidemiology and Population Health) (Hurley & Butler, 1995). It involved contributions from Niels Becker (LaTrobe University) and John Kaldor (National Centre in HIV Epidemiology and Clinical Research). The study analysed the use and costs of health services for people with HIV infection, assessed the efficiency of the Treatment and Care Program, collated expenditures on education and prevention programs, analysed the efficiency of education and prevention programs for homosexually active men, modelled the potential course of the HIV epidemic in the absence of behaviour change, and completed a study of the cost-effectiveness of the needle and syringe exchange program (the study had previously been funded under the Commonwealth AIDS Research Grants Program).

## **A.2.2 Community consultations**

In August 1994 public submissions to the evaluation were invited through advertisements in newspapers and letters of invitation. Seventy-eight individuals and organisations across the country responded; they are listed in Appendix B. The responses came from large and small community-based organisations, support groups, teachers, prison officers, religious groups, health care workers, researchers, people living with HIV/AIDS and the families and

friends of such people, and State and Territory and Commonwealth government departments. A report summarising the submissions will be published separately as an appendix to the evaluation report.

In December 1994 the Australian National Council on AIDS hosted an evaluation workshop. The workshop involved representatives of all members of the partnership. It was also attended by Professor Feachem and the evaluation team. The workshop looked at current questions and future directions in HIV/AIDS policy; this informed the evaluation. A detailed report of the workshop is available and can be obtained from the AIDS/Communicable Diseases Branch.

In February and June 1995 Professor Feachem and the evaluation team conducted a series of workshops, meetings and discussion forums in Melbourne, Sydney, Adelaide, Canberra, Alice Springs and Darwin. These consultations were designed to encourage organisations and individuals to participate in the evaluation. Six large consultation workshops were held:

- Participants in three of the workshops were State and Territory based. One workshop was for New South Wales and Victoria, another for South Australia, Tasmania and the Australian Capital Territory, and the third for Western Australia, Queensland and the Northern Territory. The workshops involved people working in various areas of service provision.
- The fourth workshop was for people living with HIV/AIDS from each State and Territory.
- The fifth workshop examined gay men's education and was attended by educators of gay men from around the country.
- The sixth workshop examined HIV/AIDS/STDs among Aboriginal and Torres Strait Islander people and was attended by representatives of the National Aboriginal Community Controlled Health Organisations, the Torres Strait Islander Advisory Board and the State Tripartite Forum (or its equivalent) in each State and Territory.

A report summarising the consultation workshops will be published separately as an appendix to the evaluation report.

In addition to the workshops, the consultation process involved a number of meetings with individuals and groups from community-based organisations, government agencies and institutions around Australia. For example, Professor Feachem met with representatives of Haemophilia Foundation Australia, the Australian Federation of AIDS Organisations, the National Association of People with HIV/AIDS, the Scarlet Alliance, the Australian Intravenous League, the Aboriginal and Torres Strait Islander Special Funds Advisory Committee in the Northern Territory, and the Legal Implementation Working Group.

A forum was also held to discuss fears of a second wave of infection among gay men, and the evaluation team consulted other groups such as the HIV/AIDS Schools Network.

### **A.2.3 Analysis of administrative data**

Apart from commissioned analysis and community consultation, information was also gathered from the project register, internal budget reports, the National Survey of School-based HIV/AIDS Education 1994, the Medicare Hospital Funding Grants, the National Reference Laboratory and other Commonwealth and State and Territory sources.

State and Territory health departments and the Commonwealth Department of Human Services and Health were sent questionnaires about the effectiveness and appropriateness of the National HIV/AIDS Strategy and about particular aspects of the Treatment and Care, Education and Prevention, and Special Funding Programs.

A case study of education and prevention programs for injecting drug users was undertaken to assess the extent to which needle and syringe exchange programs have been successfully implemented in Australia and to discuss matters affecting the effectiveness of such programs.

## APPENDIX B

# Submissions received

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- 1 Altman, Professor Dennis
- 2 Forsythe, CJ
- 3 Australian Catholic Health Care Association
- 4 anonymous
- 5 Northern Territory Department of Correctional Services
- 6 Department of Housing and Regional Development
- 7 Centre for the Study of Sexually Transmissible Diseases
- 8 ACT Corrective Services, ACT Housing and Community Services Bureau
- 9 Victorian Directorate of School Education
- 10 HIV/AIDS Accommodation Project, Western Australian AIDS Council
- 11 Port Lincoln Aboriginal Health Service
- 12 Hollis, Susanne
- 13 Russell, Murray
- 14 Australian Institute of Criminology
- 15 Dr David Bradford, Sexual Health Program, Peninsula and Torres Strait  
Regional Health Authority, Queensland Health
- 16 Prostitutes Association of the Northern Territory for Health, Education and  
Referral Inc.
- 17 anonymous
- 18 Dental Faculty, University of Sydney
- 19 South Australian Health Commission
- 20 Palmer, Dr WA
- 21 Australian Bisexual Men's Association Inc.
- 22 Deeks, David
- 23 Roberts, David
- 24 Berry, Stephen
- 25 School of Health, University of New England
- 26 Adelaide Diocesan AIDS Council
- 27 Queensland Corrective Services Commission
- 28 Douglas Shire Community Services Association
- 29 anonymous

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- 30 The Association of Independent Schools of Queensland Inc.
  - 31 New South Wales Users and AIDS Association
  - 32 Aboriginal and Torres Strait Islander Commission, Health and Community Development Branch
  - 33 Phuc Pham, Van
  - 34 Positive Women, Victoria
  - 35 AIDS/STD Unit, Victorian Department of Health and Community Services
  - 36 Department for Education and Children's Services, South Australia
  - 37 Economic and Policy Analysis Division, Department of Employment, Education and Training
  - 38 Walker, Mark
  - 39 Department of Immigration and Ethnic Affairs
  - 40 New South Wales Department of Education
  - 41 AIDS Research and Reference Centre, Australian Catholic Bishops Conference
  - 42 National Catholic Education Commission
  - 43 Communicable Disease Control Unit of Western Australia
  - 44 HIV/AIDS and Sexual Health Section, Queensland Health
  - 45 Australian Nursing Federation
  - 46 Ethnic Communities Council of Qld Ltd
  - 47 Family and Friends
  - 48 Sword, John, Rainbow Academy of Metaphysics
  - 49 New South Wales Department of Corrective Services
  - 50 Victorian AIDS Council/Gay Men's Health Centre
  - 51 Drug and Alcohol Services Council, South Australia
  - 52 Northern Territory Department of Education
  - 53 Darling Downs Regional Health Authority
  - 54 AusAID
  - 55 HIV/AIDS International Development Network of Australia
  - 56 Australian Federation of AIDS Organisations
  - 57 Correctional Services Division, Department of Justice, Victoria
  - 58 Banner, D
  - 59 Leitch, K, Councillor/Educator, Richmond Health District, Sexual Health Services, New South Wales
  - 60 McDonagh, Kerry
  - 61 HIV/AIDS Nurses Melbourne, Victoria
  - 62 Haemophilia Foundation Australia
  - 63 Surgeon General, Australian Defence Force

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- 64 Commonwealth AIDS Research Grants
  - 65 Ree, Dr H, AIDS Medical Unit, Brisbane North Region, Community Health Services
  - 66 AIDS Council of Central Australia
  - 67 Australasian Society for HIV Medicine Inc.
  - 68 Koori Health Unit, Department of Health and Community Services, Victoria
  - 69 National Association of People Living with HIV/AIDS
  - 70 New South Wales Department of Health, AIDS/Infectious Diseases Branch
  - 71 International Working Group for the former National Centre in HIV Social Research
  - 72 Prostitutes Collective of Victoria
  - 73 Family Planning Australia
  - 74 Family Planning NSW Ltd
  - 75 Education Department of Western Australia
  - 76 New South Wales Health Areas and District HIV Coordinators
  - 77 Central Australian Aboriginal Congress Inc.
  - 78 AIDS/Communicable Diseases Branch, Department of Human Services and Health

## APPENDIX C

# Management of the evaluation

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Professor Richard Feachem and the AIDS/Communicable Diseases Branch evaluation team undertook the evaluation of the National HIV/AIDS Strategy. The following individuals drafted the evaluation report: Brendan Gibson, Helen Longbottom, Frances Byers, Catherine Standen and Beverley Sibthorpe. The following individuals also worked on the evaluation team: Fran Collyer, Ellen Wood, Dave Turner, Kris Fisher, Kim White and Samantha Marriage.

Professor Feachem and the AIDS/Communicable Diseases Branch evaluation team were supported by an evaluation advisory committee appointed by the Intergovernmental Committee on AIDS. The committee advised on all aspects of the evaluation methodology and commented on drafts of the evaluation report. It was chaired by Peter Read (Chairperson, Intergovernmental Committee on AIDS) and its members were: Phil Carswell (Queensland Department of Health), Chris Brook (Victorian Department of Health and Community Services), Helen Evans (Commonwealth Department of Human Services and Health), Felicity Young and Lou McCallum (Australian Federation of AIDS Organisations), Jennifer Ross (Haemophilia Foundation Australia), Alan Brotherton (People Living With AIDS NSW), Mark Counter (National Association of People with HIV/AIDS), Marilyn McMurchie (Australasian Society for HIV/AIDS Medicine), Ross Duffin (Australian National Council on AIDS), Don Grimes (Chairperson, Australian National Council on AIDS), Susan Kippax (National Centre in HIV/AIDS Social Research), John Kaldor (National Centre in HIV Epidemiology and Clinical Research), Phil Hagan (SA Development Commission) and Adam Stankevicius (Community Information and Referral Centre of the ACT).

The evaluation advisory committee met every six to eight weeks on the following dates: 5 September 1994, 6 December 1994, 23 February 1995, 21 April 1995, 23 June 1995 and 7 August 1995.

Steering committees were established to manage the feasibility study for conducting an economic analysis of the Strategy, the economic analysis of the Strategy, and the reviews of social and behavioural factors relating to the transmission of HIV/AIDS. Members of the evaluation advisory committee sat on these steering committees, as did Geoff Woolcock (Queensland AIDS Council) and John Western (University of Queensland). A working group of the evaluation advisory committee helped plan the evaluation consultations.

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# Glossary

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## **Acquired immunodeficiency syndrome (AIDS)**

A syndrome defined by the development of serious opportunistic infections, neoplasms or other life-threatening manifestations resulting from progressive HIV-induced immunosuppression.

## **AIDS councils**

Community-based organisations established to provide education, support and care for people infected with HIV or at risk of infection.

## **AIDS-defining illness**

One of the opportunistic infections, neoplasms or conditions that indicate advanced HIV-associated immunosuppression.

## **Australian Federation of AIDS Organisations**

The peak organisation representing State and Territory AIDS councils, the National Association of People with HIV/AIDS, the Australian Intravenous League and the Scarlet Alliance.

## **Australian Intravenous League**

The national organisation representing educational and support groups for injecting drug users.

## **Australian National Council on AIDS**

The Commonwealth Government's key advisory body on HIV/AIDS, established to provide independent and expert advice to the Minister for Health on the implementation of the National HIV Strategy. It is principally concerned with the identification of national needs, objectives and priorities and takes a public information role on HIV/AIDS issues.

## **Australian National Diagnosis Related Group**

A means of classifying hospital patients to provide a common basis for comparing factors such as cost-effectiveness and quality of care across hospitals. Each diagnosis-related group represents a class of patients with similar clinical conditions requiring similar hospital services.

**Australasian Society for HIV Medicine**

A society of doctors, scientists and health care workers involved with HIV/AIDS.

**Base case, best case, worst case**

Economic evaluation of health care programs is surrounded by uncertainty concerning the effectiveness of an intervention in terms of its impact on health and the costs of the intervention. Therefore, results are usually presented using three different sets of assumptions. The base case considers the most plausible set of values for the relevant variables, presenting the mostly likely outcome of the program; the best case considers the most favourable set of values; and the worst case considers the most unfavourable set of values.

**Case management**

An individual or organisation takes responsibility for coordinating the delivery of a range of medical and non-medical services to a particular client.

**Casemix**

An information tool involving the use of scientific methods to build and make use of classifications of patient care episodes.

**Clinical trial**

A research activity that is designed to test a drug or treatment to establish efficacy and safety, and to identify groups of patients who can be expected to benefit from such drug or treatment.

**Cohort study**

A research method whereby the same individuals are studied over time.

**Communicable diseases**

An illness caused by a specific infectious agent or its toxic products and that arises through transmission of that agent or its products from an infected person, animal or other reservoir to a susceptible host.

**Community care**

Care provided in the community as opposed to within an institutional setting. The care may be delivered by professional or volunteer carers, or both, and is often provided in the patient's home.

**Community development**

An approach to working with the community that aims not only to actively involve the community in dealing with the problem at hand but to increase the capacity of the community to deal with any future problems that arise. In the specific field of HIV/AIDS such an approach is used to establish community norms and standards that support health-enhancing behaviours.

**Cost–benefit analysis**

Cost–benefit analysis of health care interventions requires a monetary value to be placed on the reduction in illness or death caused by interventions. If the benefits of a program exceed the costs, the program will lead to an increase in economic welfare.

**Cost-effectiveness analysis**

Technique of economic evaluation designed to provide evidence on whether productive efficiency is being achieved. In health care programs, output measures are commonly expressed in terms of deaths averted, or life-years saved. No monetary value is placed on the output as such and no inference can be drawn as to whether the output is ‘worth producing’.

**Cost-utility analysis**

A variant of cost-effectiveness analysis that has been developed for use in the health sector. All life-years saved are not assumed to be identical (as in cost-effectiveness analysis) but are adjusted to reflect differences in the quality of life of individuals during those years of life.

**Culturally appropriate**

A term used to describe activities and programs that take into account the practices and beliefs of a particular social group, so that the programs and activities are acceptable, accessible, persuasive and meaningful.

**Diagnosis Related Group**

*see* Australian National Diagnosis Related Group.

**Direct costs**

Those costs associated with the management or treatment of an illness; for example, medical practitioner services, pharmaceuticals and hospital services.

**Discounting**

Used in economic evaluation to take into account preferences for present over future consumption of goods.

**Discrimination, HIV/AIDS-related**

Any unfavourable treatment on the basis of known or imputed HIV status; any action or inaction that results in a person being denied full or partial access to otherwise generally available services or opportunities because of known or imputed HIV status. The definition includes discrimination on the grounds of known or imputed membership of certain groups most commonly associated with HIV and AIDS.

**Early intervention**

An approach to treatment characterised by action in the early stages of a condition; for example, treatment designed to delay the onset of AIDS in an HIV-positive patient.

**Efficiency**

In economic evaluation, the word usually refers to productive efficiency, which is achieved when any particular output level of a good or service is produced at minimum attainable cost.

**Epidemiology**

The study of the distribution and determinants of health-related states or events in specified populations and the application of this study to the control of health problems.

**Gay man**

A homosexually active man who identifies himself as gay or is attached to the gay community, or both. Individuals can alter both their self-definition and the level of their community attachment over time. Education and prevention programs typically distinguish between gay men and other homosexually active men.

**Haemophilia Foundation Australia**

The peak national body representing State and Territory community-based organisations for people with haemophilia and their families.

**Health maintenance**

Refers to an approach to HIV/AIDS that specifically promotes the benefits of testing for evidence of HIV infection and the subsequent continuing management and monitoring of an HIV-positive person's health with the intention of delaying the onset of AIDS and reducing the severity of AIDS-related illnesses.

**High-risk behaviour**

*see* Risk practice.

**Homosexually active man**

A man who engages in male-to-male sexual behaviour, regardless of whether he identifies himself as gay, heterosexual or bisexual.

**Hospital Funding Grants**

Grants provided by the Commonwealth to the States and Territories under the Medicare agreements to assist in the financing of hospitals.

**Human immunodeficiency virus**

A human retrovirus that leads to AIDS.

**Human Rights and Equal Opportunity Commission**

A Commonwealth tribunal that, among other duties, hears complaints brought under the Disability Discrimination Act.

**Immunocompromised**

A person whose immune system is suppressed. This can be due to a range of factors including HIV infection.

**Implementation Working Group**

Joint working party established by the Commonwealth Ministers for Justice and Health to monitor the implementation of the recommendations of the Legal Working Party.

**Incidence**

The number of new cases of a disease in a defined population, within a specified period.

**Indirect costs**

Costs caused by an illness but not directly associated with its management; for example, lost production due to disability or premature death.

**Intergovernmental Committee on AIDS**

A standing committee of the Australian Health Ministers Advisory Council. It provides a forum for regular Commonwealth and State and Territory liaison and coordination on policy, finance, programs and activities related to HIV/AIDS. Membership comprises an independent chairperson nominated by

the Australian Health Ministers Advisory Council, two representatives of each of the Commonwealth, State and Territory departments responsible for health, and one representative of each the departments responsible for health in Papua New Guinea and New Zealand.

### **Legal Working Party**

Established in 1990 as a sub-committee of the Australian National Council on AIDS to make recommendations on uniform national law reform in relation to legal matters associated with HIV/AIDS.

### **Mainstreaming**

An approach to service delivery characterised by a move from specialist HIV/AIDS services towards increasing the capacity of the entire system to deliver appropriate services.

### ***Mycobacterium avium* complex**

An opportunistic infection called non-tuberculosis mycobacterial disease. An AIDS-defining illness.

### **National Association of People Living with HIV/AIDS**

The peak national organisation representing people who are HIV positive.

### **Needle and syringe exchange programs**

Authorised programs that distribute, dispose of or sell needles and syringes.

### **Opportunistic infection**

Infection with an organism or organisms that are normally innocuous, but which become pathogenic when the body's immune system is compromised, as happens in AIDS.

### **The partnership**

The close working arrangement between Commonwealth, State and Territory and local governments, the affected communities and the medical, scientific and health care professions that has characterised Australia's approach to the HIV/AIDS epidemic.

### **Parliamentary Liaison Group**

A non-partisan forum through which information is provided to members of the Commonwealth Parliament and in which policy discussions can occur.

**Peer education**

Any education process devised and implemented by members of a population sub-group specifically to alter the behaviours and attitudes of other members of that sub-group; for example, gay men delivering gay education programs.

***Pneumocystis carinii* pneumonia**

Often fatal but largely preventable pneumonia among immunocompromised individuals, including HIV patients. PCP is an AIDS-defining illness.

**Prevalence rate**

The total number of all individuals who have an attribute or disease at a particular time or period divided by the population at risk of having the attribute or disease at this time or midway through the period.

**Primary prophylaxis**

Treatment or drugs to prevent a person having their first outbreak of a disease.

**Project register**

A database used by the Commonwealth Department of Human Services and Health to collate and analyse data provided by the States and Territories for projects funded under the Matched Funding and Special Funding Programs.

**Prophylaxis**

Treatment or drugs intended to prevent an infection or disease.

**Quality-adjusted life-year**

A measure of the output of a health care program, weighting life-years lived according to the quality of life experienced during those years.

**Risk practice**

Any behaviour, sexual or otherwise, that is capable of transmitting HIV.

**Safe sex, safe sexual practice**

Sexual activity in which there is no exchange of body fluids such as semen, vaginal fluids or blood.

**Scarlet Alliance**

National forum of organisations representing the interests of sex workers.

**Secondary prophylaxis**

Treatment or drugs to prevent the return of an illness; often referred to as maintenance treatment.

**Seroconversion**

The development of a detectable level of antibodies that occurs after a person has been exposed to and becomes infected by a micro-organism, such as HIV.

**Sex worker groups**

Community-based organisations representing people who work in the sex industry.

**Surveillance**

The continuing scrutiny of all aspects of occurrence and spread of a disease. Its main purpose is to detect changes in trends or distribution in order to initiate investigative or control measures.

**User groups**

Community-based organisations representing the interests of injecting drug users.

# Abbreviations

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AFAO	Australian Federation of AIDS Organisations
AIDAB	Australian International Development Assistance Bureau—now AusAID
AIDS	acquired immunodeficiency syndrome
ANCA	Australian National Council on AIDS
AN-DRG	Australian National Diagnosis Related Group
AusAID	Australian Agency for International Development
AZT	anidothymidine, also known as zidovudine
CARG	Commonwealth AIDS Research Grants
DRG	Diagnosis Related Group
HFA	Haemophilia Foundation Australia
HFG	Hospital Funding Grants
HIV	human immunodeficiency virus
HSDS	Highly Specialised Drug Scheme
IDU	injecting drug user
IGCA	Intergovernmental Committee on AIDS
LWP	Legal Working Party
MAC	<i>Mycobacterium avium</i> complex
MFP	Matched Funding Program
NAPWA	National Association of People Living with HIV/AIDS
NEP	National Education Program
NHMRC	National Health and Medical Research Council
NPP	National Priorities Program
PCP	<i>Pneumocystis carinii</i> pneumonia
PLWHA	people living with HIV/AIDS
SFP	Special Funding Program
STD	sexually transmitted disease
TB	tuberculosis
UNAIDS	United Nations World Program on AIDS—formerly the Global Program on AIDS
UNDP	United Nations Development Program
WHO	World Health Organisation