a policy discussion paper

AIDS
A TIME TO CARE
A TIME TO ACT

Towards a strategy for Australians

POLICY DISCUSSION PAPER

AIDS:

a time to care
a time to act

Towards a strategy for Australians

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Contents

List of Figures and Tables viii

Notes on terminology ix

Introduction 1

Executive summary 5

1 THE CHALLENGE 38

1.1 The epidemic of HIV infection and HIV-related illnesses 39

1.1.1 The global epidemic 39
1.1.2 The epidemic of HIV infection in Australia 41
1.1.3 HIV-related illnesses in Australia 42
1.1.4 Predicting the spread of AIDS 48

1.2 Transmission of the human immunodeficiency virus 50

1.2.1 Sexual transmission 50
1.2.2 Perinatal transmission 53
1.2.3 Transmission by blood 54
1.2.4 Modes which have not been implicated in transmission 57
1.2.5 Conclusion 59

1.3 Clinical manifestations and natural history of HIV infection 60

1.3.1 Natural history of infection with HIV 60
1.3.2 Infection with HIV 61

1.4 Behaviour change in response to the epidemic 67

1.4.1 Evidence of behaviour change 67
1.4.2 Factors influencing behaviour change 69

1.5 Cost and human resource implications of HIV 73

1.5.1 Introduction 73
1.5.2 Costing the epidemic 73
1.5.3 Costing programs of intervention 82
1.5.4 Human resource requirements 83

2 A NATIONAL RESPONSE 86

2.1 The need for an agreed national response to the epidemic 87

2.2 Objectives of a National AIDS Strategy 89

2.3 Guiding principles proposed for the development of a National AIDS Strategy 90

3 OBJECTIVE 1: To minimise transmission of the Human Immunodeficiency Virus (HIV) 94

3.1 Minimising the spread of HIV 95

3.1.1 Sexual transmission 96
3.1.2 Transmission through the sharing of needles and syringes 97
3.1.3 Perinatal transmission 98

3.2 The role of education in minimising transmission 100

3.2.1 Education for prevention 100
3.2.2 A national education strategy 101

3.3 Other public health measures 108

3.3.1 Testing to minimise transmission of HIV 108
3.3.2 Contact tracing 114
3.3.3 International travel and immigration 115
3.3.4 Procedures following death 120
3.3.5 Condom standards and availability 120
3.3.6 Compulsory treatment 122
3.3.7 Immunisation 123

3.4 The role of the law 124

3.4.1 The role of the law in minimising transmission of HIV 124
3.4.2 Legal impediments to prevention programs 125
3.4.3 Knowingly transmitting the virus 126
3.4.4 Education of workers in the legal system 127

3.5 Prevention strategies for priority groups 128

3.5.1 Homosexual and bisexual men 128
3.5.2 Needle sharing drug users 131
3.5.3 Aboriginal and Islander people 137
3.5.4 People in prison 138

3.5.5 People in other closed institutions 141
3.5.6 Adolescents 143
3.5.7 Women 146
3.5.8 People who work as prostitutes 147
3.5.9 Blood transfusion and blood product recipients 149

3.6 HIV infection and the workplace 151

3.6.1 Policy development 151
3.6.2 Occupational transmission 153
3.6.3 Workplace education to minimise transmission 155
3.6.4 Personnel policies and practices relating to minimising ransmission 156

4 OBJECTIVE 2: To support, care for, and to treat people infected with HIV 160

4.1 Educational measures for the support of infected people 161

4.1.1 Living with infection: education for infected individuals 161
4.1.2 Living with infection: education for the wider community 162

4.2 Strategies relating to the health of infected individuals 164

4.2.1 The provision of care 164
4.2.2 Counselling 165
4.2.3 Self-help groups 166
4.2.4 Nutrition 166
4.2.5 Treatment of HIV infection and related illnesses 168
4.2.6 Needs of particular infected populations 171

4.3 Infected individuals as a part of the community 174

4.3.1 Infants and children with HIV infection 174
4.3.2 Employment, education and training 176
4.3.3 Income maintenance 180
4.3.4 Access to housing 182
4.3.5 Life insurance 184
4.3.6 Health insurance 186
4.3.7 Superannuation 187
4.3.8 Compensation 189

4.4 Health and community services planning 192

4.4.1 Case management 192
4.4.2 Provision of counselling services 193

4.4.3 Planning for the neurological aspects of HIV infection 194
4.4.4 Location and organisation of treatment 195
4.4.5 Planning for service delivery 197
4.4.6 Human resource planning 198
4.4.7 Training requirements 199
4.4.8 The role of community groups 200
4.4.9 The role of volunteers 201

4.5 Legal protection for infected individuals 204

5 OBJECTIVE 3: To educate and to prevent infection of people who care for HIV-infected individuals 208

5.1 Education of carers of infected individuals 209

5.2 Protective work policies and practices 211

5.2.1 Infection control procedures 212
5.2.2 HIV testing in health care settings 217

5.3 Supportive work practices 219

5.4 Legal issues in health care settings 221

6 INTERNATIONAL COOPERATION 223

6.1 The international political community 224
6.2 The development assistance agenda 226

7 RESEARCH TO SUPPORT A NATIONAL AIDS STRATEGY 230

7.1 The requirement for research 231

7.1.1 Research goals 231
7.1.2 Research priorities 232
7.1.3 Research arrangements 233

7.2 Monitoring the spread of the epidemic 235

7.2.1 National epidemiological database requirements 235
7.2.2 Monitoring AIDS 236
7.2.3 Monitoring HIV infection 236
7.2.4 Monitoring groups at higher risk 240
7.2.5 Monitoring the whole population 240
7.2.6 Diagnostic assays 242

7.3 Research for minimising transmission of the virus 244

7.3.1 Prevention programs for higher risk groups 244
7.3.2 National education program 245
7.3.3 Research on a vaccine and cure 246

7.4 Research for the care, support and treatment of infected individuals 247

7.5 Research for the education and protection of carers 249

7.6 Research for costing and resource planning 250

8 MONITORING AND EVALUATING A NATIONAL AIDS STRATEGY 253

Bibliography 257

Appendixes

1 Classification of HIV infection 272

2 Resolution WHA40.26 of the Fortieth World Health Assembly: Global strategy for the prevention and control of AIDS 275

3 Resolution WHA41.24 of the Forty-first World Health Assembly: Avoidance of discrimination in relation to HIV-infected people and people with AIDS 280

Index 284

Figures

1 Annual incidence of reported AIDS cases and their mortality, Australia 1982 to 1987 44

2 Annual incidence of reported AIDS cases by age group, Australia 1985 to 1987 47

3 Breakup of total program related costs identified 1986–87 80

4 Actual and budgeted HIV-dedicated expenditure by State health authorities 1986–87 and 1987–88 81

5 Framework of cost components 251

Tables

1 AIDS cases reported and related deaths, Australia, by transmission category and year of diagnosis, 1982 to end of 1987 45

2 AIDS cases diagnosed in 1987, by States, Territories and sex 47

3 Projection of incidence of AIDS cases, Australia, 1988 to 1990 49

4 HIV-infected health-care workers with no reported non-occupational risk factors and for whom case histories have been documented in the scientific literature 57

5 HIV-dedicated expenditure by the Commonwealth Department of Community Services and Health 1984–85 to 1988–89 76

6 HIV-related costs summary, Australia, 1986–87 79

7 Net cost of a single case of HIV infection, illustrative calculation 83

Notes on terminology

AIDS	The term AIDS (Acquired Immune Deficiency Syndrome) refers only to a subset of the illnesses which may occur after infection with the HIV virus. It was defined by the Centers for Disease Control, USA and the definition adopted by Australian authorities. More detail can be found in Appendix 1.
AZT	Antiviral agent whose chemical action is to inhibit replication of HIV. Now named zidovudine, formerly azidothymidine. Its trade name is Retrovir.
Bisexual men	Men who have sexual relations with both women and men. This includes men who normally relate sexually to men but who may also have sexual relations with women, as well as men who may be married to or normally have sexual relations with women but who may also have sexual relations with men.
Cofactor	A factor, other than the basic causative agent of a disease, that increases the likelihood of developing that disease.
Contact Tracing	The identification and notification of people who may have infected, or have been at risk of infection from, a known infected person.
Epidemic	The occurrence of a group of illnesses of a similar nature clearly in excess of normal expectancy.
Epidemiology	The study of the distribution of a disease and of the factors which influence the distribution.
Gay men	A subgroup of homosexual men who identify themselves with the gay community. It is a reference to membership of a community sharing a common identity more than to behaviour.
HIV	The term "HIV" is the universally agreed name for the Human Immunodeficiency Virus, the virus responsible for the epidemic. The virus was previously referred to as LAV (Lymphadenopathy-associated virus); HTLV-III (Human T-Cell Lymphotropic virus type III) and ARV (AIDS-related virus). The phrase "the HIV virus" has been used at times to facilitate the reading of the text.
HIV-related illness	The range of illnesses which may occur as a result of HIV infection. It replaces previously used expressions such as

	AIDS-related condition (ARC) and includes those illnesses referred to as AIDS.
Homosexual men	Men whose sexual orientation is towards other men. Their sexual activities are exclusively with males.
Incidence	The number of new cases of infection or illness in a given population within a particular period of time.
Needle and syringe sharing drug use	The activity which places intravenous drug users at risk of infection with HIV is the sharing of unsterile needles, syringes or, possibly, other equipment.
Prevalence	The number of cases of infection or illness in a given population at a particular point in time.
Retroviruses	A family of viruses, which includes HIV, characterised by the method of replication in the cells they infect. This replication involves the transfer of genetic information in a direction which is the reverse of that which usually occurs.
Safer sex	Sexual activity where transmission of HIV by semen, blood, vaginal or cervical secretions is minimised. This may be through a change in sexual practices or through the correct use of quality condoms.
Seroconversion	The appearance of antibodies to the HIV virus. This usually occurs between 6 and 12 weeks after infection.
Seropositive or HIV-positive person	A person who has antibodies to HIV, as revealed by testing.
Testing	The testing of blood or other tissues to find out if antibodies to the HIV virus are present or to isolate the virus.

Introduction

Introduction

Australia is facing the possibility of a serious epidemic of human immunodeficiency virus (HIV) infection. This could cause immense suffering and have major economic and social consequences. However, such an epidemic is not inevitable: the ways of preventing transmission of the virus are known. What is needed is the desire on the part of the Australian community, and each of its members, to ensure that preventive measures are followed.

The presence of HIV is a public health problem affecting every Australian. By 11 October 1988, 1023 cases of the severest manifestation of HIV infection, AIDS, had been reported in Australia. Thousands more people are infected. Some may know that they are infected; some may not. All face the probability of serious illness and death. While most are in their early adult years, some are infants and children, some are elderly.

The appearance of the virus has changed our lives. The HIV epidemic will be able to be brought to an end through the development of an effective vaccine or cure or by preventing transmission of the virus. This will probably not be achieved in the near future. In the meantime, each individual will need to live in such a way as to prevent infection and its consequences.

The epidemic is changing the way people relate to each other sexually and socially. Infected people have tapped unexpected sources of compassion and care: more and more people are offering to help them to live as full and as satisfying lives as they can.

The presence of the virus, highlighting as it does issues such as sexuality, drug use and discrimination, is bringing moral issues into prominence. Many in the community who wish to offer compassion or care to those affected may experience conflict with their moral beliefs and need help to resolve it.

Soon many will know, or know of, an infected friend, acquaintance, or family member and may be confronted with the nature of their dying. This has already produced fear. Such fear is reasonable and could be a strong motivating force to preventing infection and its consequences, and to changing behaviour to prevent transmission. Many will need encouragement and support to change their behaviour and governments will need to provide that assistance.

Australia's efforts to date in containing the spread of the virus have achieved national respect and international recognition. Our comprehensive, practical, rational and often brave response to AIDS has

enabled Australia to implement policies and programs which are as humane and as compassionate as they are medically and socially sound.

Although we may never know the measure of our early successes, there is no doubt that lives have been saved and suffering reduced by our national maturity and strength. But the real test is yet to come, a test which will demand continuing support from the whole Australian community.

This Discussion Paper has been written to help individual Australians, public health authorities and governments to consider and agree on the best possible ways of working together to minimise transmission of the virus and to support, care for and treat those infected with it.

The aim of this Paper is to encourage and provoke informed debate on appropriate responses to the epidemic and to assist in the analysis of possible policy components. Community discussion of the issues is important to promote agreement and to reach a consensus on the best way of responding. The Paper does not make recommendations but identifies and discusses a range of possible policy components for achieving the objectives.

The first part of the Paper sets out what is known about the presence of the virus in Australia, the way infection affects people, what behaviour and factors make people vulnerable to infection, the financial cost so far, and what human resources have been required. It provides the factual information needed to understand the nature of the problems and to elicit appropriate responses.

The second part provides a possible framework for a national AIDS strategy. It proposes three broad objectives for a national strategy: to minimise transmission of the HIV virus; to support, care for and to treat people infected with the HIV virus; and to educate and prevent infection among people who care for infected individuals.

Because many of the issues on which policies are needed are extremely complex, the Paper identifies some key principles to guide the development of policy. Agreement on these principles by governments and the community will be a significant step towards agreement on the national response.

The last part of the Paper deals with Australia's involvement in the international response to the global pandemic, with the research needed to support a national AIDS strategy and with monitoring and evaluating the Strategy's programs.

For each of the broad objectives, the Paper identifies a range of possible policy components. Each component listed is to be assessed for its ability to contribute towards the achievements of the objectives of the strategy. Many of the components may be rejected during the course of the community and

governmental discussion of the issues. Some components are clear alternatives; others are complementary.

The Paper is structured by the proposed objectives rather than by topics. So a topic may be addressed under more than one objective. For example, measures to minimise transmission in prisons are discussed under Objective 1, but measures required because of the presence of infected prisoners in the prison system are discussed under Objective 2. Those whose primary interest lies in a particular area will thus need to read across the Paper with the index as a guide.

The importance and the urgency of developing an agreed response to the presence of the HIV virus is recognised in the tabling of this Discussion Paper in all Houses of Parliament in Australia. The tabling will be followed by extensive consultations between governments and with community groups and the general public to gain early agreement on the precise components of a national AIDS strategy. The governments of each State and Territory and the Commonwealth share a commitment to respond swiftly and effectively, taking into account the informed wishes of the community.

A national AIDS strategy should comprise those policy components which will most effectively assist us to stem the epidemic and to provide compassionately for those infected during its course. As a community we have the responsibility to inform ourselves and to choose the best way to respond. It is the hope of all governments that this Discussion Paper will begin the process.

Executive summary

Objectives of a National AIDS Strategy

Three objectives for a National AIDS Strategy are proposed:

1 To minimise transmission of the Human Immunodeficiency Virus (HIV).

2 To support, care for and to treat people infected with HIV.

3 To educate and to prevent the infection of people who care for HIV-infected individuals.

Guiding principles proposed for the development of a National AIDS Strategy

A number of principles are proposed to form a basis on which policies should be formulated. Under certain circumstances there will be exceptions to some principles or particular principles may need to be overriden or modified. However, any departures should be carefully justified.

The guiding principles are:

Policies should be formulated on the basis that transmission of the virus is preventable.

Extensive understanding of the nature of the epidemic is essential to the development of sound policies.

Each person must accept personal responsibility for preventing himself or herself becoming infected through sexual intercourse or through sharing of needles and for preventing further transmission of the virus.

The Australian community has the right to access to appropriate protection against infection.

Educational measures and prevention programs can bring about behavioural changes to minimise transmission.

The law can complement and assist education and other public health measures.

To be effective, policies will require the continuing cooperation of those at risk of infection.

People infected with HIV retain the right to participate in the community.

Confidentiality regarding a person's HIV infection status should be maintained.

Specific informed consent should be obtained before any test is performed to diagnose a person's HIV infection status.

People infected with HIV have the same rights to comprehensive and appropriate health care, income support and community services as other members of the community.

Carers for HIV-infected people have a right to protective and supportive working environments and a responsibility to minimise occupational transmission.

Objective 1: To minimise transmission of the Human Immunodeficiency Virus (HIV)

Minimising the spread of HIV (3.1)

In the absence of a vaccine or cure, education to change risk behaviour remains the primary means of minimising transmission. Preventive measures include securing blood and blood product supplies, ensuring adequate production standards and accessibility of condoms and distributing sterile injecting equipment. These measures, along with the removal of legislative and social barriers to the required behaviour change, are needed to complement and reinforce education programs.

The role of education in minimising transmission (3.2)

Education about HIV needs to reach every Australian. Progress can be made towards achieving this objective with the development and resourcing of a comprehensive and consistent national education program. Not all people are at the same level of risk of infection, nor is it likely that sufficient human and financial resources would be available immediately. Highest priority for education programs should continue to be given to those currently most at risk of becoming infected or of transmitting the virus to others. However, a national education strategy cannot be limited only to these groups since the transmission of HIV to others outside these groups has begun.

Developing programs which differ in resource input according to individual or group risk status, or the program's potential to influence prevention, is

the most appropriate course for HIV education in Australia. These should be developed through the most effective combination of Commonwealth, State, Territory and community mechanisms and must be carefully monitored and evaluated.

Possible policy components

- Develop programs:
  - for those who are currently thought to be at higher risk of infection with HIV;
  - for those who are considered most likely to be at risk in the near future;
  - for all Australians, regardless of risk status;
  - which differ in resource input according to individual or group risk status;
  - which differ in resource input according to the program's potential to minimise transmission.
- Develop and deliver such programs:
  - at Commonwealth, or State and Territory levels;
  - at community level;
  - at all levels;
  - through a mix of levels depending on effectiveness and outreach.
- Establish monitoring and evaluation procedures to assess effectiveness and outreach.

Other public health measures (3.3)

Testing to minimise transmission of HIV (3.3.1)

A number of measures to minimise HIV transmission have been proposed including education and prevention programs for people known to be infected, counselling to prevent infection or further transmission, compulsory treatment, legal sanctions against knowingly transmitting the virus and quarantining of infected people. Implementing these measures depends upon knowledge of a person's infection status. The most reliable method of determining a person's HIV status is to test for the presence of antibodies to the virus or of the virus itself.

The use of testing to establish a person's HIV infection status raises serious considerations relating to consent to testing, confidentiality and counselling which apply to testing for any purpose.

Possible policy components

- Provide voluntary testing for anyone wishing to be tested.
- Actively and widely encourage voluntary testing.
- Test the whole population on a compulsory basis.
- Test people believed to be at higher risk of infection on a compulsory basis.

- Test pregnant women or women considering pregnancy, with specific consent.
- Test pregnant women or women considering pregnancy, without specific consent.
- Following a positive test, minimise transmission by:
  - providing counselling and education in order to encourage appropriate behaviour change;
  - quarantining infected people;
  - excluding infected individuals from particular activities.

Contact tracing (3.3.2)

Identification and notification of those who may have been placed at risk of infection is normally undertaken by the infected individual, who may request assistance from primary caregivers. Occasionally contact tracing is conducted by trained members of government agencies, in a confidential and sensitive manner, and with consent of the individual.

Possible policy components

- Place responsibility for tracing sexual or needle sharing contacts of a known infected person with:
  - the infected person, after counselling on how best to do it;
  - primary caregivers;
  - public health authorities.
- Notify, either on a compulsory or discretionary basis, those perceived to be at immediate risk from a known infected person.

International travel and immigration (3.3.3)

The rapid global spread of HIV is linked to the mobility of modern travellers. The Commonwealth would need to consider each of the policy components in terms of their effectiveness, the costs and benefits of their introduction, practicality, and human rights and international diplomacy issues.

Regular reviews of current policies on international travel and immigration are needed to assess whether they are consistent with containing the further spread of the virus.

Continued HIV education aimed at travellers and immigrants before they arrive in Australia, and wide dissemination of safer behaviour guidelines to Australians departing the country is essential.

Possible policy components

- Continue current Australian policy whereby prospective immigrants, refugees and longer-term temporary entrants are asked to consent to HIV

testing only if it is clinically indicated or as a result of specific questions relating to risk of HIV infection; a positive HIV test result is a cause for recommending rejection on health grounds.
- Test all entrants to Australia for HIV, or test selected groups or people from geographical areas known to be associated with high levels of HIV, with, following a positive test:
  - automatic exclusion;
  - review of applications on a case by case basis.
- Educate all travellers leaving, entering or returning to Australia about transmission of HIV.

Procedures following death (3.3.4)

Procedures for handling human remains must be designed to minimise occupational risk of transmission. However public health regulations have imposed severe restrictions. This frequently causes distress to relatives and friends of the deceased. Procedures adopted should recognise to the maximum extent possible the needs of those who are grieving.

Possible policy components
- Develop uniform and sensitive guidelines for handling HIV-infected bodies and for funeral arrangements.
- Treat all non-cremated human remains imported into Australia, whether bodies or tissues, as potentially infectious.

Condom standards and availability (3.3.5)

Rubber condoms, when properly used, have been shown to be effective in reducing the risk of transmission of HIV.
Restrictions on the availability of suitable condoms should be removed, and adequate standards and manufacturing quality controls regularly reviewed and strictly maintained.

Possible policy components
- Review the standards that apply to rubber condoms for adequacy as a barrier to HIV.
- Apply these standards to all condoms.
- Ban condoms unsuitable for use as an HIV barrier.
- Remove limitations on the availability of condoms.
- Produce and label condoms to specify use for particular sexual activities.

Compulsory treatment (3.3.6)

Historically, compulsory treatment has been instituted for a few communicable diseases, notably tuberculosis, to reduce the risk of infection to others. However, HIV is not a contagious airborne infection; infection is

for a lifetime; and there is no treatment available which reduces a person's infectivity. In such circumstances, compulsory treatment is not an appropriate measure.

Possible policy component

- Consider compulsory treatment for HIV infection if it can be shown that treatment reduces infectivity.

Immunisation (3.3.7)

A vaccine against HIV is not expected to be available in the timeframe of this strategy. However, consideration could be given to issues which would be raised by a national immunisation campaign.

Possible policy component

- Plan in advance for a national HIV immunisation campaign.

The role of the law (3.4)

The role of the law in minimising transmission of HIV (3.4.1)

The law has a role to play in minimising transmission of HIV by complementing and supporting education and prevention programs. Governments will need to determine the likely effectiveness of legal measures in minimising transmission and in protecting the rights of both infected individuals and the community.

A review is needed of existing laws relating to public health management of infectious diseases to determine their appropriateness for dealing with HIV.

Possible policy components

- Limit the role of the law to complementing and assisting education and prevention programs to minimise transmission of HIV.
- Public health related legislation to be reviewed by governments which have not already done so, including reassessment of the wide powers accorded to public health officials in legislation governing the control of notifiable infectious diseases.

Legal impediments to prevention programs (3.4.2)

Laws prohibiting particular activities associated with the transmission of HIV need to be examined with a view to removing legislative impediments to effective education and prevention programs.

Possible policy components

- Examine laws penalising homosexuality, prostitution and use of injection equipment to remove legislative impediments to preventive programs.
- Identify ways in which preventive programs and policies could be implemented within existing laws.
- Review laws relating to censorship and broadcasting standards.

Knowingly transmitting the virus (3.4.3)

Ways in which a person may knowingly place another at risk of infection with HIV include having unprotected sex with that person, sharing injection equipment, failing to follow known infection control procedures, or attacking the person in order to infect them.

A person thought likely to transmit the virus knowingly could be subject to legal penalties and sanctions or could be assisted to change their behaviour. This assistance could take the form of education and counselling or referral to a community based program designed to provide support and guidance to such people.

Possible policy components

- Impose legal penalties for knowingly transmitting the virus.
- Isolate infected people thought to be knowingly running the risk of infecting others.
- Educate and counsel on a personal basis infected people thought to be knowingly running the risk of infecting others.
- Involve community groups in support measures, counselling and guidance.

Education of workers in the legal system (3.4.4)

HIV-related matters will increasingly be brought before the legal system. These matters are complex, require extensive knowledge of the subject matter and will elicit the same range of emotions in the legal community as they do in the general community. There is a need to ensure that all legal workers are fully conversant with and educated about HIV-related issues.

Possible policy components

- Establish a regular and frequently updated system of information about HIV for legal system workers.
- Develop programs for the education of legal workers on a national basis.

Prevention strategies for priority groups (3.5)

Homosexual and bisexual men (3.5.1)

Homosexual and bisexual men remain a high priority for prevention and education programs. Education programs based in the gay community have been very successful. However, there are still substantial numbers of homosexual men who do not consistently practise safer sex.

Many men who have sex regularly or occasionally with other men do not identify as homosexual or bisexual and may have no contact with the gay community. They are especially hard to reach with educational messages and are at increased risk of infection because of their isolation.

Possible policy components

- Extend, monitor and evaluate education and prevention programs aimed at homosexual and bisexual men.
- Extend urgently education and prevention programs designed to reach homosexual and bisexual men who are not part of the gay community.

Needle sharing drug users (3.5.2)

Intravenous drug users risk infection with HIV if they share needles, syringes or any other equipment used for preparing or injecting drugs with a person who is infected with HIV.

Drug users who share injecting equipment must become a high priority group for HIV education and prevention programs. Almost all intravenous drug users report sharing injecting equipment at some time or another.

Reducing or eliminating equipment sharing practices among intravenous drug users can minimise further transmission through drug use, and consequently through the sexual activities of intravenous drug users or through perinatal transmission.

Possible policy components

- Develop or extend programs with the following objectives:
  - abstinence from drug use;
  - drug use without injection;
  - intravenous drug use without sharing;
  - sharing of only decontaminated injecting equipment.
  - Extend needle and syringe distribution and exchange programs.
- Provide information on the cleaning of used equipment to intravenous drug users, particularly

those who do not currently wish to enter drug treatment.
- Increase availability of drug treatment programs.
- Provide training courses for drug program workers and staff of other services in contact with drug users on issues arising from drug use transmission of HIV.
- Develop peer education programs to minimise transmission through sharing of equipment and through sexual behaviour.
- Include information about HIV in drug prevention programs designed for people at risk of being offered drugs.
- Continue to include occasional intravenous drug users in HIV prevention and education campaigns.
- Provide services and treatment programs for women drug users, including child care facilities, contraception and pregnancy counselling, and information on perinatal transmission of HIV.

Aboriginal and Islander people (3.5.3)

Culturally specific and appropriate measures are needed to minimise HIV infection among Aboriginal and Islander people. Policies adopted in this area should support and extend work already started, as well as assisting other Aboriginal groups and organisations to develop relevant education and prevention programs.

Possible policy components
- HIV education and prevention programs to be developed by, or in consultation with, Aboriginal and Islander people.
- Improve Aborigines' and Islanders' health, in particular health conditions which may place them at greater risk of infection.
- Increase the numbers of Aboriginal and Islander health workers and train them in the implications of HIV infection.
- Develop education programs addressing the need for community support for HIV-infected Aboriginal and Islander people.

People in prison (3.5.4)

The potential spread of HIV within prisons and from there to the community is serious and warrants policy priority. A national effort drawing on Australian and overseas expertise is needed to enable agreement to be reached on appropriate education, prevention and support initiatives.

Prevention programs will need to address issues such as condom distribution, drug treatment programs, needle distribution and exchange and the issuing of bleach for decontaminating needles.

Possible policy components

- Introduce appropriate and specific HIV education and prevention programs for all inmates and for new inmates on arrival.
- Introduce education programs to educate prisoners on release about HIV transmission in the wider community and specifically in their own relationships.
- Introduce education programs, within the framework of employment training, for all prison officers.
- Provide access for prisoners to condoms, either by the introduction of condom vending machines or distribution by other means.
- Introduce needle and syringe exchange programs and/or distribute information and the supplies needed to decontaminate equipment.
- Provide access to methadone programs for intravenous drug using prisoners .
- Provide voluntary HIV testing for all prisoners, on entry, during their sentence and/or on release.
- Require compulsory HIV testing of all prisoners, on entry, during their sentence and/or on release.
- Segregate prisoners identified as HIV positive.

People in other closed institutions (3.5.5)

Measures are needed to minimise the risk of infection for patients and staff in closed institutions. Information about HIV transmission should be accessible to all people in closed institutions, complemented by the development of guidelines to deal with people infected with HIV. Other measures could include the availability of condoms.

Possible policy components

- Provide HIV education and counselling programs for staff and for those in their care and their families designed to meet the needs of people in closed institutions.
- Provide access to condoms, but under supervision for people
- with intellectual or mental disabilities.
- Provide access to sterile needles, but under supervision for people with intellectual or mental disabilities.
- Amend government guidelines for closed institutions to acknowledge the implications of HIV transmission.

Adolescents (3.5.6)

As the epidemic spreads in the general community, adolescents will become particularly vulnerable to infection. Adolescence is a time of experimentation with a range of behaviours, both social and sexual, and intense conformity to peer group norms.

Reaching young people with messages about HIV prevention will require the development of programs for diverse media and educational settings. Significant consultation with young people is essential.

Possible policy components

- Develop education and prevention programs for adolescents outside educational settings through venues, youth workers, mass and other media, and youth cult personalities.
- Encourage school and other educational communities to set an example to children and adolescents in the appropriate responses to HIV-infected students.
- Educational institutions to develop material which is honest, explicit and comprehensive about the options which are available for preventing HIV infection.
- Youth training centres and correctional institutions to develop education and prevention programs which take into account the special needs of these adolescents.
- Support youth workers to help them educate and counsel young people about HIV transmission and risk behaviours.

Women (3.5.7)

Women will be increasingly placed at risk of infection. They will need assistance to develop skills in negotiating sexual and drug use situations and in communicating their decisions to others. Education and prevention programs designed for girls and women need to be supported.

Possible policy components

- Identify the sexual, social and economic factors which place women at risk of infection.
- Educate women on preventing transmission of HIV, and train them in the skills required to protect themselves.
- Mobilise women to help minimise transmission:
  - through their control of sexual and drug use situations;
  - through women's organisations;
  - as educators of children and adolescents;

- as community models and sources of information.
- Provide access to counselling for women who have, or whose partners may have, a history of high risk behaviour, including counselling about perinatal transmission.

People who work as prostitutes (3.5.8)

Governments need to recognise the complex issues surrounding prostitution and develop flexible approaches to minimising the spread of HIV among people who work as prostitutes and their clients. Legislation, regulations and policing practices which prevent the establishment of prostitutes collectives or work against attempts to minimise the spread of HIV in these groups may need to be reviewed.

Possible policy components

- Assist in developing further an infrastructure to deliver HIV education and prevention programs.
- Educate prostitutes, clients and brothel owners on means of preventing transmission and on cofactors of transmission.
- Extend the program of safe houses.
- Review legislation, regulations and practices which may impede HIV education and prevention programs among prostitutes and their clients.

Blood transfusion and blood product recipients (3.5.9)

Health authorities should continue measures to prevent HIV infection of people with haemophilia and blood transfusion recipients, and further transmission to their sexual partners. This can be done by specifically targeting education and counselling programs, by continuing to secure the blood and blood product supply and by encouraging those who received blood transfusions or blood products between 1980 and 1985 to come forward for counselling and testing.

Possible policy components

- Actively encourage counselling and testing for all people who received blood transfusions or blood products between 1980 and 1985.
- Ensure continued quality control in the screening of blood, blood products and organ donations.
- Continue educating and counselling people with haemophilia, infected blood transfusion recipients, their families and partners.
- Develop appropriate education and prevention programs for infected adolescents with haemophilia.

- Continue support for the HIV education and counselling services provided by the Haemophilia Foundation of Australia.
- Expand services to infected blood transfusion recipients and their partners and families.

HIV infection and the workplace (3.6)

Policy development (3.6.1)

Employers and unions both need to address the changing conditions brought about by HIV in policies on the prevention of transmission in the workplace. These will include the promotion of adequate occupational health and safety policies, the formulation of personnel policies, including confidentiality and the prevention of discrimination, and workplace education programs to counter prejudice and fear from other employees or third parties such as customers.

Possible policy components

- Develop HIV-related occupational health and safety policies.
- Establish close links between employers, unions and health authorities on HIV-related matters.

Occupational transmission (3.6.2)

The vast majority of workers are at no risk of acquiring HIV infection at work. Only workers directly exposed to blood or body fluids could be at risk. The adoption and observance of sensible precautions can minimise or eliminate any risk of occupational transmission.

Possible policy components

- Institute appropriate occupational health and safety policies in all workplaces to minimise or eliminate any occupational risk of HIV transmission.
- Legislate to require minimum safety and sterilisation standards in commercial settings involving skin penetration.

Workplace education to minimise transmission (3.6.3)

The most effective way to avoid unnecessary disruption in the workplace is to prepare and educate both management and employees before any individual is infected. Education programs need to be continually updated, to address fear and discrimination, and be sensitive to the concerns of employees.

Possible policy component

- Employers in both the public and private sectors to develop education programs in advance of any HIV-related problem in the workplace.

Personnel policies and practices relating to minimising transmission (3.6.4)

The relatively small number of infected people in the workplace allows organisations the opportunity to develop an HIV workplace strategy acceptable to management and unions well in advance of having to deal with specific cases.

Possible policy components

- Expand existing personnel policies and practices relating to serious illness to cover HIV-related issues.
- Establish HIV-specific personnel policies and practices in such areas as health and safety standards, overseas travel and postings, employer conduct and review and appeal procedures.

Objective 2: To support, care for and to treat people infected with HIV

Educational measures for the support of infected people (4.1)

Education and counselling services need to be provided to enable individuals to cope with diagnosis and to learn to live with their health status. Public education will be an important strategy for enabling infected individuals and their families to live in the community without fear and without stigmatisation.

Possible policy components

- Provide education programs including counselling, peer support programs and self-help groups for infected people to assist them to learn to live with infection.
- Establish professional standards for HIV educators through, for example, accreditation procedures for educators.
- Educate those in the wider community through programs to promote understanding and compassion towards those infected.

Strategies relating to the health of infected individuals (4.2)

The provision of care (4.2.1)

The Commonwealth and State Governments have joint responsibility for providing a wide range of health care and community services. People infected with HIV are entitled to benefit from all existing relevant services, and where appropriate, special services could be established.

Possible policy components

- Use relevant existing health and community welfare services, with the establishment of special services where appropriate.
- Develop special services for HIV-infected people separate from existing services.

Counselling (4.2.2)

The systematic application of counselling in prevention and management is one of the more important strategies available to deal with HIV infection. It can minimise the cost of care and treatment by helping people to manage many of their psychological and physical health problems themselves.

Possible policy components

- Provide an adequate number of trained counsellors.
- Provide systematic counselling at time of diagnosis, for adjustment to diagnosis and for loss and bereavement.

Self-help groups (4.2.3)

Self-help groups for people affected by HIV are important in terms of their health and well being and the ability to control their lives. They can also assist in coping with the effects of social stigmatisation and discrimination.

Possible policy component

- Assist HIV-infected people to develop self-help organisations responsive to their particular needs.

Nutrition (4.2.4)

Good nutrition can improve the health status of HIV-infected people and may delay the onset of HIV-related illnesses. Research into nutrition and HIV infection could lead to improvement in patient care, prognosis and life expectancy.

Possible policy component

- Develop programs to establish and monitor good nutritional status throughout HIV infection and illness.

Treatment of HIV infection and related illnesses (4.2.5)

Treatment must only be given with the informed consent of the individual or his or her legal guardians.

The only anti-retroviral treatment approved for use in Australia is AZT, which is the most effective agent currently available. Trials are planned for two other drugs. People with HIV infection are in need of current information on the efficacy and availability of the range of treatments directed against HIV.

Many HIV-related illnesses are preventable or treatable although treatment is often expensive and ongoing preventive therapy necessary.

A number of non-approved treatments are being promoted for HIV infection and HIV-related illnesses which may have potentially serious toxic effects. There is a need to provide adequate information and protection to consumers on these treatments.

The importance of factors that may influence progression of disease such as nutrition, stress, drugs and other concurrent infections has been recognised in some treatment programs. Access to such programs is being sought by HIV-infected people.

Possible policy components

- Expand the range of treatments available in Australia, either through importation or local production.
- Provide current advice to infected people on the efficacy and availability of treatments.
- Continue availability of AZT only through approved public hospitals and clinics.
- Ban the advertising of ineffective substances as treatment for HIV infection or related illnesses.
- Provide access by people with HIV infection to complementary and alternative treatments which have no potentially serious toxic effects.

Needs of particular infected populations (4.2.6)

Models of care for infected people have been developed in response to the health needs of homosexual men because they are the overwhelming majority of all those infected. Other infected individuals may have different health needs because of different disease manifestation or progression, or because of other considerations. These needs should also be addressed.

Possible policy components

- Establish support groups and counselling services for HIV-infected drug users and assistance to gain access to methadone and treatment programs.

- Train Aboriginal health care workers in community based care, and recognise the wish of Aboriginal and Islander people to be cared for in their communities and buried on their land.
- Refer HIV-infected prisoners to treatment and support services on release.
- Release HIV-infected prisoners early.
- Assist infected women to establish support and self-help groups.
- Provide access to abortion for pregnant HIV-infected women.
- Provide counselling for people with haemophilia who are considering having children.
- Provide access to medical services and procedures including surgery for infected people with haemophilia.
- Provide HIV treatment and related services to infected people with haemophilia within a haemophilia treatment program.

Infected individuals as part of the community (4.3)

Infants and children with HIV infection (4.3.1)

While the number of children who are HIV-infected is small, it will grow, primarily through increasing levels of HIV infection among female intravenous drug users.

Authorities responsible for or involved in the care of children in the community and in institutions should develop appropriate policies and services for children who are HIV-infected, their families and other carers and provide education programs to allay fear of infection.

Possible policy components

- Authorities responsible for schools, pre-schools and child care centres to provide guidelines for staff, parents and children to address HIV-related issues including fear of infection, confidentiality, care and safety.
- Provide education on the implications of HIV for people who work with infected children and for parents of other children.
- Government authorities responsible for adoption and fostering to recognise that policies may need to be reviewed to take into account the implications of HIV infection among infants and children.

Employment, education and training (4.3.2)

HIV-infected people need equal access to employment, and to education and training which enables them to find employment and to stay employed for as long as possible.

For most infected people, the opportunity to continue working even part-time is important both economically and psychologically. Without employment, infected individuals are a direct burden on social welfare and may suffer higher rates of progression to illness. Employers should formulate policies to address the effects of HIV infection. These could be complemented by legislation against discrimination in the workplace.

Possible policy components

- Governments, employers and unions to formulate education, employment and training policies for HIV-infected persons which support and encourage a normal working life.
- Test for HIV to exclude infected individuals from employment, or from employment in certain occupations.
- Legislate or adopt codes of practice to provide redress in case of discrimination against HIV-infected people or their families and friends in employment, education and training.
- Private and public sector organisations to develop personnel policies and practices for employment of HIV-infected staff which cover confidentiality, testing, dismissal, leave conditions, fitness for work and employee conduct.

Income maintenance (4.3.3)

Income maintenance mechanisms need the flexibility to encourage continuance in employment and to accommodate movement in and out of the workplace by HIV-infected people according to the state of their health. Their interests and those of the community are best served by their leading normal productive lives.

Current income maintenance mechanisms should be examined to determine whether they are appropriate for people with HIV infection or whether additional benefits are required.

The delivery of services to HIV-infected people and procedures for maintaining confidentiality need to be reviewed.

Possible policy components

- Review current income maintenance and related health card benefits to determine whether

adjustments are appropriate because of HIV-related illness.
- Introduce a flexible allowance or benefit arrangement to enable, in combination with existing benefits, infected people to remain in the workforce or return after periods of invalidity.
- Train staff in the area of income maintenance to ensure HIV-infected people are treated without prejudice and that procedures to ensure confidentiality are instituted and strictly implemented.

Access to housing (4.3.4)

The policies of public and private sector housing administrators toward people whose circumstances change should take into account the particular difficulties of HIV-infected people and their families, who may experience variations in income, discrimination and increased health care costs. Assistance could be provided in the context of existing housing programs with, if necessary, modifications to meet the special needs of infected people.

Possible policy components
- Involve both the public and private sectors in determining mechanisms by which HIV-infected people can remain in their own accommodation for as long as feasible and desirable.
- Provide public rental housing, in the same way as for other disadvantaged people, and wherever possible near treatment and day care centres.
- Public housing authorities to spot purchase homes of HIV-infected people to allow them continued occupancy.
- Use existing State housing assistance programs to assist HIV-infected people to stay in their own homes.
- Modify existing programs to allow for special needs of HIV-infected people.

Life insurance (4.3.5)

Since HIV infection shortens life expectancy, it has a direct impact on life insurance. Issues confronting insurers and proposers include ensuring that unfair or irrational discrimination is avoided, that confidentiality is maintained, that claims are promptly and correctly settled, and that the interests of proposers, insurers and other policy holders are protected.

Possible policy components
- Rely on market forces to shape the industry's response.

- Government and the entire life insurance industry to agree on a voluntary code of practice to deal with HIV-related issues.
- Extend existing insurance legislation to eliminate unfair or irrational discrimination and to address issues such as confidentiality and testing.
- Establish an insurance complaints unit.
- Establish mechanisms to assist HIV-infected people to continue premium payments after loss of income.

Health insurance (4.3.6)

The Australian health insurance industry operates under a community rating principle which ensures that all contributors are treated equally regarding contribution rates and entitlements.

Almost all persons with HIV-related illnesses are treated under Medicare in the specialist AIDS units located in public hospitals. Some concern has been expressed by private health insurers that a significant increase in the number HIV-positive people joining health funds under the current arrangements for pre-existing ailments will result in increasingly frequent claims for hospitalisation.

Possible policy components

- Maintain health insurance arrangements for HIV-related conditions as for any patient or illness.
- Maintain the current arrangements applying to pre-existing ailments for health insurance of HIV-positive people.

Superannuation (4.3.7)

Superannuation fund managers need to examine ways of providing superannuation coverage to HIV-infected individuals which protects their employment prospects and benefit entitlements as well as the viability of the fund.

Possible policy components

- Develop a code of practice for superannuation funds similar to that adopted by the insurance industry.
- Provide benefits to employees who are HIV-infected.

Compensation (4.3.8)

Compensation for HIV-infection, however infection has been acquired, is not an issue on which there will be easy consensus.

There is a need to determine whether compensation should be paid, and if so, by whom and to whom.

Possible policy components

- Medically acquired HIV infection to be regarded as being no different from other medically acquired and sometimes fatal conditions which are not subject to any government compensation scheme, on the grounds that there are extensive income maintenance and other benefits provided by governments for all eligible persons, without regard to the cause of invalidity or loss of employment.
- Governments to pay compensation to infected individuals or their families to cover consequences such as loss of income, denial of insurance, extra treatment and home care costs and loss of quality of life.
- Pay compensation only to those who acquired HIV infection solely through medical intervention.
- Pay compensation to all who acquired HIV infection before modes of transmission were identified and publicly known.
- Establish a special assistance fund to enable grants to be made on a case by case basis.

Health and community services planning (4.4)

Case management (4.4.1)

Case management procedures should be designed to take into account the range of HIV-related conditions from infection to death, and to provide maximum coordination of all individuals and organisations involved in the treatment, care and support of an HIV-infected person.

The concept of a continuum of care has been promoted as an appropriate model. It implies a network of services working in a complementary manner to offer infected individuals a consistently good level of care, information, education and support.

Possible policy component

- Develop case management procedures to ensure a continuum of care with maximum coordination and cooperation of all involved in the care and treatment of HIV-infected people.

Provision of counselling services (4.4.2)

Planning is needed to ensure that comprehensive and consistent counselling services will be available to all HIV-infected people and their carers, families and close friends. This will require the coordination of existing government and non-government services. Inadequacies in present arrangements will need to be identified and overcome, and appropriate training made available.

Possible policy components

- Plan to ensure that adequate numbers of trained counsellors are available for HIV-infected people, health care workers and other caregivers.
- Health departments to consider appointing HIV Counselling Coordinators.
- Provide training in counselling issues relating to HIV for:
  - all counsellors who wish to work in this field;
  - HIV-dedicated counsellors.

Planning for the neurological aspects of HIV infection (4.4.3)

Service and human resource requirements for dealing with the psychological and neuropsychiatric aspects of HIV infection need to be determined. Carers and health professionals working with HIV-infected people need to understand the possible central nervous system manifestations of infection. Access and referral processes and appropriate treatment and management measures are needed.

Possible policy components

- Determine the human resource and service requirements arising from neuropsychiatric aspects of HIV infection.
- Educate all involved in the care of those infected about the psychological and psychiatric aspects of infection.

Location and organisation of treatment (4.4.4)

Patients requiring treatment for HIV-related illnesses will present in all areas of medical practice and the health care system. Some will require treatment for conditions not related to HIV infection and others will be treated for conditions which at first are not recognised as being due to HIV. A cooperative effort will be required involving medical personnel, hospitals, home and hospice care, and day care centres to provide the necessary services.

Possible policy components

- Develop a network of service provision to deal with the consequences of HIV infection to include inpatient hospital wards, specialised treatment units, outpatient services, home and hospice palliative care settings and day care services.
- Locate clinical units for people with HIV-related illnesses in general teaching hospitals only, or in all hospitals.

- Establish separate facilities to provide hospital and hospice care for people with AIDS and other HIV-related illnesses.
- Treatment services to be carried out by specialists in conjunction with general practitioners and other community health care providers.

Planning for service delivery (4.4.5)

Detailed analyses of the requirements of people infected with HIV need to be undertaken so that planning for service delivery can occur. Because of the nature of HIV and because infected people may have health and community service requirements unrelated to their HIV status, this should take place in the context of broad service delivery planning. Existing services can often be adapted and expanded to deal with the particular needs of HIV-infected people.

Possible policy components

- Analyse service requirements for those infected with HIV.
- Identify requirements which can be met through existing services.
- Establish separate services if required.

Human resource planning (4.4.6)

Detailed human resource planning is needed across the broad range of relevant disciplines to ensure that the specialist carers needed to manage HIV infection are available.

Possible policy components

- Plan future human resource requirements for the care of infected people.
- Determine case load limits and procedures for when limits are exceeded.

Training requirements (4.4.7)

The identification of short, medium and long-term training requirements is necessary. Agreement on proper accreditation procedures and ongoing in-service training to update knowledge could help attract professionals to work in the area.

Possible policy components

- Develop short, medium and long-term training systems, pre-service and/or inservice, to cope with current and future needs in the HIV service delivery area.
- Develop HIV-related curricula.
- Credit HIV-related work by health care workers as part of their training.

- Establish a clearinghouse for information about HIV for health care workers.

The role of community groups (4.4.8)

Community based organisations have played, and will continue to play, a critical role in the provision of HIV care, support and education. These organisations need to be supported to cover all groups at increased risk of infection. Their ability to respond to community needs will depend on continuing and increased financial assistance from all levels of government.

Possible policy components

- Continue support and funding from all levels of government to community based organisations.
- Community based organisations to develop flexible management and strategic plans.

The role of volunteers (4.4.9)

The essential role played by volunteers in providing care, support and education about HIV should be recognised and supported.

A mixture of professional and volunteer services will be necessary in the coming years. Volunteers provide direct care and support services and are also a vital source of advice and support for the informal network of family and friends who usually care for and support HIV-infected people.

Possible policy components

- Voluntary organisations to become incorporated bodies to enable appropriate insurance to cover the organisation and its associated volunteers.
- Extend workers compensation provisions to provide protection for health and welfare voluntary workers.
- Legislate to indemnify volunteers from liability for negligence in the course of providing services.

Legal protection for infected individuals (4.5)

Two major areas of concern relating to the rights of individuals are the protection provided by the law from unjustified discrimination and protection from misuse of personal information.

Effective methods for the protecting people from discrimination and breaches of confidentiality involve the provision of adequate education to all people, and of guidelines for those who handle confidential information. However there may be a need in some circumstances for recourse to legal alternatives.

Possible policy components

- Consider legislative means for ensuring confidentiality including legal requirements to

develop systems to limit the dissemination of confidential material.

- Establish, extend or clarify anti-discrimination legislation in all jurisdictions, either specific to HIV-infected people or covering them under general provisions, including provisions against discrimination against family or carers of infected people.

Objective 3: To educate and to prevent infection of people who care for HIV-infected individuals

Education of carers of infected individuals(5.1)

Education programs are needed to provide carers of infected people with the specific skills they require if they are to participate effectively in the management of HIV. Carers need accurate information on protective work policies and practices; on supportive work practices; and the provision of quality care. Participation in client, peer and community education is important. Attitudinal and environmental barriers to safe and supportive work practices should also be addressed.

Possible policy components

- Provide adequate and appropriate HIV-related education as part of the accreditation process in institutional settings such as hospitals and pathology services.
- Provide similar programs for non-institutional and less clinical settings, such as residential drug and alcohol treatment agencies and home care services.

Protective work policies and practices (5.2)

Infection control procedures (5.2.1)

All appropriate steps should be taken to protect from occupational transmission of HIV all persons who are caring for, or providing health services to, an HIV-infected person.

The risk of acquiring HIV infection from work activities in any health care setting is very low. The extent to which this already low risk can be further reduced depends on how rigorously infection control and accident prevention procedures are applied.

Possible policy components

- Apply universal infection control and accident prevention procedures.
- Develop and implement infection control and accident prevention procedures tailored to the requirements of each health care environment.
- Make hospital accreditation conditional on the rigorous application of infection control procedures.
- Provide access for police and other emergency workers such as firefighters and ambulance personnel to comprehensive, factual and practical education about transmission of HIV and its prevention.

HIV testing in health care settings (5.2.2)

HIV testing for health care workers and for patients has been advocated by a number of people. It is the responsibility of public health authorities to protect those caring for HIV-infected persons from occupational transmission. The primary focus should be on infection control and accident prevention measures. Testing of patients and staff may, in some circumstances, be an ancillary measure. The benefits of knowing a person's infection status need to be weighed against the possibility of harm to the individual in the event of a breach of confidentiality.

Possible policy components

- Routinely test all health care workers and patients, either on admission to hospital or before providing health care such as major surgery.
- Actively encourage voluntary testing and the rigorous application of infection control and accident prevention procedures.
- Involve public health authorities, community groups and those calling for testing in the determination of an agreed policy.

Supportive work practices (5.3)

People caring for HIV-infected individuals assume a degree of responsibility and face a range of medical and ethical problems greater than that encountered with most other patient groups. This can induce severe psychological and physical stress. It is important that work practices which support both employed and voluntary staff be established.

Possible policy components

- Expand formal training in medical ethics to health care workers and medical students to cover HIV-related ethical issues.

- Improve working conditions for those involved in care, including shorter working hours and staff rotation.
- Involve a broad range of disciplines in the provision of care.
- Provide supportive services such as counselling and support groups to those involved in care.

Legal issues in health care settings (5.4)

Health care workers and institutions need to be aware of their legal rights and responsibilities as they are confronted with issues raised by HIV infection. These rights and responsibilities need clarification in some areas.

Possible policy components

- Determine the legal rights and responsibilities of health care institutions and health care workers.
- Educate health care workers and health care institutions in their legal rights and responsibilities and in ways of meeting them.

International cooperation

The international political community and development assistance agencies will be challenged to respond to the growing problem of HIV infection throughout the world. Australia needs to continue its leading role in future international political considerations of HIV-related issues in order to assist in securing an effective international response.

Australia should continue to respond promptly to requests to provide direct assistance to countries in our immediate region and to assist other countries through the WHO Global Programme on AIDS.

Possible policy components (6.1 and 6.2)

- Continue Australia's active role in the discussion of HIV-related issues in the international political community.
- Continue support for the work of the WHO Global Programme on AIDS.
- AIDAB to be involved in all donor meetings convened in the South Pacific, South East Asia and the Indian Ocean Island States held to coordinate support for HIV prevention and control activities.
- Continue funding HIV-related activities through the South Pacific Multi-Country Program and consideration of similar programs in South East Asia and the Indian Ocean Island States.

- Develop a capacity in the Department of Community Services and Health to respond to small-scale, non-project requests from developing countries for HIV-related assistance.
- AIDAB to encourage and support the interest of non-government organisations in HIV-related activities in developing countries.

Research to support a national AIDS strategy

The requirement for research (7.1)

Research has a vital role to play in support of a National AIDS Strategy. The success of this Strategy will depend on the quality of the research base on which it can draw to develop policies, design and implement programs and evaluate their effectiveness and impact.

Considerable research at a high standard has already been undertaken in Australia on HIV-related topics in the biomedical and social sciences. The national research effort now needs to be extended to enable it to provide further support for all involved in Australia's response to the epidemic. This can be done both through our own research efforts and by transferring to Australia the advances made elsewhere.

Priorities will need to be identified through a process of consultation among health officials and other practitioners, community groups and researchers. Selection of research projects for funding will depend on a number of factors, including their relevance, the expertise of the researchers, methodological considerations and the importance placed on them by the community.

Possible policy components

- Establish HIV-related research priorities.
- CARG to continue as the major adviser on Commonwealth funded HIV-related research.
- Support research into HIV-related biomedical, epidemiological and social areas.
- Promote research in relevant fields in which Australia does not have an established research base through:
  - commissioned research;
  - assigning funding preference to those areas;
  - establishing a Special Unit in Social and Educational HIV-related Research;
  - scholarships;
  - workshops and working parties.

- Include data collection and program evaluation components in all HIV-related programs funded by governments.

Monitoring the spread of the epidemic (7.2)

Estimating the prevalence and incidence of infection, and determining epidemiological factors which underlie infection, is vital for understanding the nature of the problem, formulating effective responses, costing of policy and for making projections of future costs and caseloads.

Existing collections of data about HIV infection will need to be analysed and improved, and new programs of testing for epidemiological purposes may be needed. Data should, to the maximum extent possible, be presented by factors such as age, sex and mode of transmission

Possible policy components

- Monitor the national epidemiological data collection to ensure that future data needs can be met.
- Educate the population as a whole on the purpose and importance of gathering HIV-related epidemiological data.
- Limit testing to accredited laboratories to ensure the provision of standard data to the national data base.
- Determine HIV infection levels in the population as a whole through regular testing of the entire population or of a randomly selected sample of the population.
- Monitor trends in seroprevalence levels by:
  - collecting data on groups at higher risk, in particular people who attend STD clinics and drug programs or people in prison;
  - analysing data gathered for non-epidemiological purposes, for example testing done by the Australian Defence Force and insurance companies;
  - testing a group of people or a cluster of groups which could stand as proxy for the general population.
- Testing to be done:
  - voluntarily;
  - mandatorily;
  - compulsorily.
- Testing to be done:
  - with the results linkable to individuals;
  - anonymously.
- Continue support to maintain a high standard of technical excellence in diagnostic assays.

Research for minimising transmission of the virus (7.3)

Strategies to minimise further transmission of the virus will be based on education and prevention programs to establish and reinforce safer behaviours. The success of the national education strategy will depend on the quality of research about the target audience, the prevalence of risk behaviour and the incentives and barriers to change. Research is required for the adequate design, monitoring and evaluation of these programs. Research into the development of a vaccine and cure will, in the longer term, assist in achieving the same objective.

Possible policy components

- Undertake research into factors underlying risk behaviour and which influence and support behaviour change.
- Undertake educational research based on social research and interaction with target groups.
- Undertake research towards the development of a vaccine and cure.

Research for the care, support and treatment of infected individuals (7.4)

The primary requirement for planning for service provision is for comprehensive studies of the range of needs, physical, psychological, financial and others, experienced by HIV-infected persons and their carers.

Much more needs to be known about the natural history of infection, including studies of those infected people in whom the disease has not progressed, and those who have learnt to live productively with infection. Clinical trials of a wider range of promising treatments need to be initiated. Research into nutrition and HIV infection could lead to improvement in patient care, in prognosis and life expectancy.

The forms of cognitive impairment associated with HIV infection, including AIDS dementia, need to be further studied and issues relating to loss, dying and bereavement need to be addressed as part of the psychosocial aspects of care provision.

Possible policy components

- Undertake comprehensive research into the physical, psychological and financial needs of people infected with HIV.
- Undertake research in the clinical manifestation and natural history of HIV infection, including HIV-related cognitive impairment.

- Undertake research related to the treatment and management of HIV infection, including chemotherapy and nutrition.

Research for the education and protection of carers (7.5)

Research is needed to assist in designing HIV education programs for health care workers and other carers, and into the design and implementation of infection control procedures which would ensure their maximum acceptance in the workplace.

Most care of infected persons is provided by untrained partners, friends and family members working in isolated and difficult conditions. Research into the needs of, and services required by, carers themselves should be undertaken.

Possible policy components

- Undertake research into the knowledge and attitudes of those who care for infected people and their educational needs.
- Undertake research into the development of approved protective materials and devices.
- Undertake research into the implementation of infection control procedures to increase their acceptance in the workplace.
- Undertake research into the needs of carers and services required by them.

Research for costing and resource planning (7.6)

More comprehensive costing and resource studies of the epidemic are needed. Costing methodologies need to be sufficiently flexible to take into account the changing nature of the epidemic, and should satisfy both the goals of accounting and of costing policy measures.

Possible policy components

- Determine the magnitude of the various components of costs arising as a result of the epidemic.
- Estimate the relative costs and benefits of different strategies of prevention and treatment.

Monitoring and evaluating a national AIDS strategy

The economic and social implications of HIV infection mean that the public policy response at all levels of government should be constructive and effective, and publicly accountable. All programs and activities need to be

adequately monitored and evaluated for their efficiency and effectiveness, and the results used in developing further public health measures.

Possible policy components (8.1)

- Develop a monitoring and evaluation body within the Commonwealth Department of Community Services and Health or the Australian Institute of Health.
- Establish a monitoring and evaluation committee under the aegis of the Australian Health Ministers' Conference, the Premiers' Conference, or the Australian National Council on AIDS.

The challenge

1.1 The epidemic of HIV infection and HIV-related illnesses

1.1.1 The global epidemic

The human immunodeficiency virus (HIV) is a human retrovirus discovered by French researchers in 1983. It is now widely accepted that infection by HIV is the cause of the epidemic of the acquired immune deficiency syndrome (AIDS) and related illnesses, first reported in the United States in 1981 and now evident in all parts of the world.

The epidemic of HIV infection has spread globally with great rapidity, although the number of reported cases is still small. The World Health Organization's Global Programme on AIDS conservatively estimates that over 150 000 cases of AIDS occurred around the world in the decade to 1987. It is likely that several times this number of people have milder forms of HIV-related illnesses. Using available data, WHO estimates that approximately 150 000 new cases of AIDS will occur during this year. The number of new AIDS cases during 1988, therefore, may equal the total number of cases which have occurred before that year. Between now and the early 1990s, WHO estimates that between half a million and three million cases of AIDS could occur globally. However, at this stage, the evolution of this epidemic cannot be predicted with accuracy.

Serological surveys show that infection by the virus is present in all parts of the world and widespread in many. Current estimates are that one to two million people are infected with HIV in North America and as many as six to eight million in Africa. The actual magnitude is unknown but further global spread and increase in numbers of HIV infections are certain. It is therefore likely that the coming decade will see a large increase in the number of HIV-related illnesses, including AIDS, in most parts of the world.

The virus is transmitted in the same ways but in varying degrees throughout the world, and the range of behaviours which place people at risk of infection is the same. In all countries, the greatest numbers of those infected have been adults in their economically productive and child-bearing years. However, the current manifestations of the epidemic are not identical throughout the world.

Although many people behave in ways which could allow transmission to occur, there may be few people in their societies who are infected and so there is little transmission. But it remains true that the behaviour of these people places them potentially at risk of infection, a potential which could be realised if larger numbers of people in those populations become infected. For example, the same sexual behaviour in Sydney or Kinshasa, Zaire,

carries a different risk of transmission because more sexually active people in Kinshasa are infected. Other factors, such as the duration of infection and possibly the presence of certain other sexually transmitted diseases, may also influence the extent of the risk.

Different patterns also arise when populations at risk of infection are closed. Very different patterns would emerge if an infected person shared needles and equipment with only a few friends, as compared with random needle sharing in large intravenous drug taking populations. Infection spreads much more widely in the latter case. Similar variations occur with sexual transmission in closed and open populations.

Differences in HIV epidemiological patterns also occur because of economic and technological differences between countries. Infection through the blood or blood product supply, or through the use of non-sterile equipment in medical contexts, is now a very rare occurrence in most developed countries. This is not true in the many countries without the financial or human resources to secure their blood supply or medical equipment and practices. It is estimated that up to 20 per cent of all cases of HIV infection may occur in this way in sub-Saharan Africa.

The epidemiological pattern with which we are most familiar, that of Western Europe, North America, Australia, New Zealand and parts of South America, is one in which the virus was first found in male homosexuals, and soon after in people with haemophilia, intravenous drug users and blood transfusion recipients. Most HIV infection has occurred in adult males, between 20 and 40 years old, in urban areas. Perinatal transmission has begun to be reported as infection in women increases.

Sexual transmission has been predominantly through anal intercourse between homosexual men, although there is evidence that the rate of transmission by these means is decreasing. Transmission through vaginal intercourse has occurred and is increasing in incidence although currently it accounts for only a small proportion of sexually acquired HIV infection in these countries. HIV transmission through blood transfusion or blood products is not a continuing problem. Transmission through blood now mainly occurs among intravenous drug users.

A second pattern is found in Africa, principally Central, Eastern and Southern Africa, and also in parts of the Caribbean. In this pattern, the major route of transmission is also sexual, but transmission occurs predominantly through vaginal intercourse between heterosexual couples. In these areas there are approximately equal numbers of infected men and women. Blood borne transmission is through blood transfusion and through the widespread use of injections in both the modern and traditional health sectors. Young adults of both sexes, in both the urban and rural areas, have been infected. In some urban areas, up to 25 per cent of women and men in the 20 to 40 year age group may be HIV-infected.

As a result of the high numbers of women carrying the virus, perinatal transmission is a serious problem in these countries. In some areas, 5 to 10 per cent or more of pregnant women are HIV-infected. In one Ugandan study, 24 per cent of pregnant women were infected. Thus, significant numbers of infants and young children are infected. The difference between these first two patterns is not only in different sexual, cultural and social behaviours but also in individual and State poverty.

A third pattern is found in Asia, the Pacific, the Middle East and Eastern Europe. The HIV virus entered these populations more recently and the incidence of infection so far seems to be relatively low. Initial studies indicate that those most at risk of transmission are prostitutes, people who have received blood transfusions outside the region, and users of imported blood products. The prostitutes most at risk are men and women who have had sexual relations with non-nationals. In some countries, they are predominantly male; in others, female. There is evidence that transmission is now occurring through the sharing of drug using equipment.

There are reasons to believe that the future pattern for the Pacific may be more similar to Africa than the West. Globally the pattern may move in the same direction.

Countries with the first two of these patterns were alerted to the presence of the HIV virus only years after it first entered and began spreading through their populations. The period between initial infection of an individual and the development of observable HIV-related illnesses can be up to seven years or longer, and during this time the virus can be passed unknowingly from individual to individual.

1.1.2 The epidemic of HIV infection in Australia

Monitoring the extent of the spread of HIV infection, and in particular the rate at which it is spreading, is important for education, prevention and other intervention programs, for planning future services and human resource needs, and for estimating future costs. There is little information on the prevalence or incidence of HIV infection in the general population in Australia.

Some selected data on incidence and prevalence have been collected, for instance from blood donors. In common with other countries with similar infection patterns, Australia has not carried out regular surveys of the whole population. The overall prevalence of HIV infection is too low to justify the financial and social costs.

Other approaches have been developed. One method is to estimate the ratio of HIV-infected persons to reported AIDS cases in other countries, and to use this ratio to estimate the number of HIV-infected people. The difficulty lies in determining the ratio. WHO previously used ratios in the range 50:1 to

100:1, but these are now thought to be too high, at least for developed countries. The range in the United States is thought to lie between 20:1 and 30:1, but there are problems associated with using ratios from one population for other populations.

Another method is to determine the size of each subpopulation at risk, for example homosexual men, intravenous drug users, and to estimate the prevalence in each group. However, there are not adequate data on the size of these groups in Australia, only rough and sometimes conflicting estimates.

The most recent estimate of the prevalence of HIV infection in Australia is in the range 15 000 to 25 000. Earlier estimates were much higher, ranging from 50 000 to 100 000. The number of HIV-infected persons in the population might be as low as 10 000 or as high as 40 000 [National Workshop on AIDS Epidemiology 1988].

Information is available from notifications of HIV-infected individuals, as required by law in some States, and from testing carried out in laboratories. There are problems associated with such data: there is considerable underreporting of individuals who have a positive HIV antibody test, and laboratory data do not distinguish between numbers of tests performed and the actual numbers of individuals tested. Extrapolation of the presently available data to broader populations is complicated by strong selection biases, largely due to the fact that testing has been performed for a number of purposes not related to the collection of statistics.

Since infection is now preventable and known to be so, it is possible that current patterns of acquiring the infection may change. Some groups may become less at risk and others more so, or levels of incidence of infection may drop in all groups. These changes will determine the shape of the epidemic in Australia in the years to come.

1.1.3 HIV-related illnesses in Australia

Little is known in Australia about the prevalence or incidence of HIV-related illnesses other than AIDS. Comprehensive data on AIDS are collected on a national basis by the NHMRC Special Unit in AIDS Epidemiology and Clinical Research.

By 11 October 1988, a cumulative total of 1023 AIDS cases had been reported in Australia. Of these, 511 had died. The actual number of AIDS cases is believed to be higher than 1023, since some cases may not have been reported.

The annual incidence of reported AIDS cases in Australia by year of diagnosis and their associated mortality by 11 October 1988, also recorded by year of diagnosis, is shown in **Figure 1**. This figure shows that the number of

AIDS cases reported each year has risen from 42 in 1984, to 113, 224 and 345 in the subsequent years to 1987.

Figure 1 also shows that the risk of death increases as time from diagnosis of AIDS increases. All the people diagnosed with AIDS in 1982 and 1983 are dead. Forty one of the 42 reported cases diagnosed in 1984 are dead. Of those diagnosed in 1985, 85 per cent are dead; of those in 1986, 78 per cent; and in 1987, 46 per cent.

The overall case survival rate for Australia for cases diagnosed before 11 October 1988 was 50.0 per cent, ranging from 64.4 per cent for Victoria to 36.4 per cent for Queensland and 33.3 per cent for Tasmania. The factors responsible for the differing case survival rates have not been studied.

One patient diagnosed in 1984 was still alive in October 1988; 15 per cent of those diagnosed in 1985 were still alive over two years later. Of those diagnosed in 1986 or earlier, 68 out of 386, or 18 per cent, were still alive at 11 October 1988. At present, the median survival time in this country from diagnosis of AIDS to death is 9.5 months.

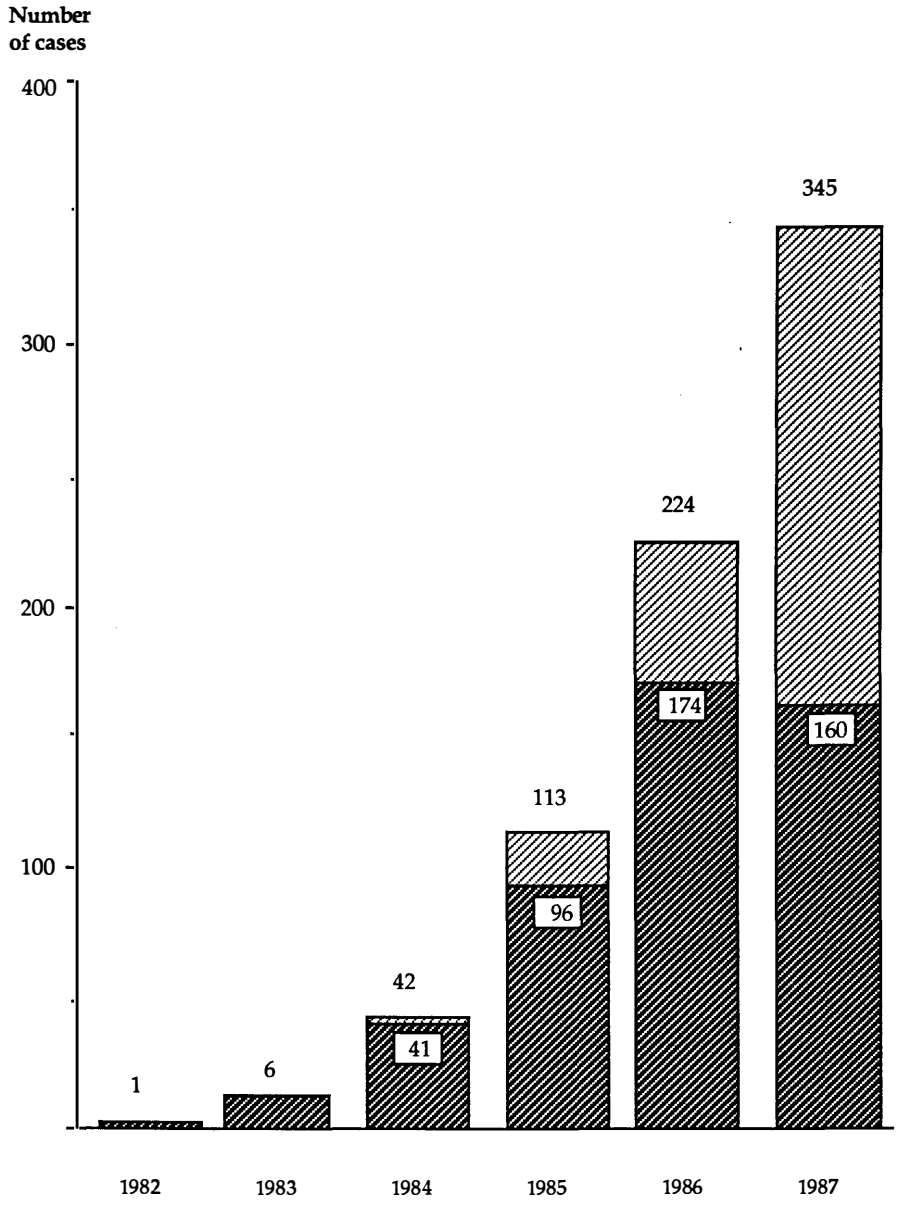
Mortality may differ by age, sex and transmission category. So far, it has been higher in the younger and older age groups, in women, and in blood transfusion and blood product recipients.

The distribution of reported AIDS cases according to the mode of transmission and by year of diagnosis to the end of 1987 is shown in **Table 1**. The large majority (86.3 per cent) of all people reported with AIDS to the end of 1987 were infected through homosexual transmission; this includes bisexuals. Of those cases diagnosed during 1987, 2.0 per cent were reported as infected through heterosexual transmission.

The classification convention adopted in Australia for the reporting of AIDS classifies transmission as heterosexual if the person's only stated sexual activity has been heterosexual, and if no other accepted or known sources of infection have been identified. Persons who have ever engaged in homosexual sexual activities or who, while exclusively heterosexual, have shared needles in intravenous drug use, are not classified under heterosexual transmission. This reporting convention may mask the extent of heterosexual transmission.

Figure 1:

Annual incidence of reported AIDS cases and their mortality[a], Australia 1982–1987



Associated deaths as at 11 October 1988

a Deaths recorded by year of diagnosis of AIDS

Source: NHMRC Special Unit in AIDS Epidemiology and Clinical Research 1988

Table 1:

AIDS cases reported and related deaths[a], Australia, by transmission category and year of diagnosis, 1982 to end of 1987

	1982	1983	1984	1985	1986	1987	Total
Homosexual transmission							
AIDS cases reported	1	4	30	99	195	302	631
Related deaths	1	4	30	84	149	136	404
Needle sharing drug use							
AIDS cases reported			1		2	1	4
Related deaths					2		2
Homosexual transmission and/or needle sharing drug use							
AIDS cases reported		2	1		12	7	22
Related deaths		2	1		9	2	14
Blood transfusion							
AIDS cases reported			7	9	13	12	41
Related deaths			7	9	13	12	41
Clotting factor							
AIDS cases reported			2	1	1	5	9
Related deaths			2	1	1	3	7
Heterosexual transmission							
AIDS cases reported				2		7	9
Related deaths				1		1	2
Transmission category other or pending							
AIDS cases reported			1	2	1	11	15
Related deaths			1	1		6	8
Total all categories							
AIDS cases reported	1	6	42	113	224	345	731
Related deaths	1	6	41	96	174	160	478
Cumulative Total							
AIDS cases reported	1	7	49	162	386	731	
Related deaths	1	7	48	144	318	478	

[a] By 11 October 1988.

Source: NHMRC Special Unit in AIDS Epidemiology and Clinical Research

At 11 October 1988, sexual transmission, both homosexual (87.7 per cent) and heterosexual (1.3 per cent), as the means of HIV infection accounted for at least 89.1 per cent of all reported AIDS cases. Needle sharing, together with the possibility of sexual contact, accounted for 3.3 per cent. Infection through blood or blood products accounted for 6.0 per cent. In the remaining cases, transmission was either under investigation or was known but not able to be clearly classified under the categories in Table 1. In all such cases, the mode of transmission was either sexual, from mother to child, through contact with blood, or by transplantation of human tissue.

The male to female ratio of reported AIDS cases to the end of 1987 was 24:1. This ratio is significantly higher than the male to female ratio for the United States (13:1) and for Europe (9:1). In Africa, the male to female ratio is probably close to 1:1.

Figure 2 shows the annual incidence of reported AIDS cases by age group in Australia from 1985 to 1987. It can be seen that the cases are heavily concentrated in the most sexually active age groups, from 20 to 49 years. The under-20 age group accounted for 1.5 per cent of the total cases and the over-60 age group for 2.7 per cent. The length of time between infection and diagnosis of HIV-related illness means that the most common ages for infection are probably five to ten years younger than these figures indicate, mainly in the age groups 15 to 35 years.

The incidence per hundred thousand of population of the reported cases of AIDS in 1987 and the percentages of total cases reported in Australia for all States and Territories are shown in **Table 2.**

The ranking of the States and Territories in terms of their case load during 1987 shows that New South Wales had 64.9 per cent of the total number of reported AIDS cases in Australia. Victoria had 21.2 per cent, Queensland 6.7 per cent, Western Australia and South Australia each 2.9 per cent, ACT 0.9 per cent and Tasmania 0.6 per cent. No cases were diagnosed in the Northern Territory.

The incidence of AIDS cases in 1987 per 100 000 of population was 4.1 in New South Wales, 1.8 in Victoria, 1.2 in the ACT, 0.9 in Queensland, 0.7 in Western Australia and South Australia and 0.5 in Tasmania. Overall, Australia had an incidence rate of 2.2 per 100 000 population in 1987.

Figure 2:

Annual incidence of reported AIDS cases by age group, Australia 1985–1987

Source: NHMRC Special Unit in AIDS Epidemiology and Clinical Research 1988

Table 2:

AIDS cases diagnosed in 1987, by States, Territories and sex

State or Territory	Total AIDS Cases Reported				Rate per 100 000 population
	Male	Female	Total	Per cent	
New South Wales	214	10	224	64.9	4.07
Victoria	71	2	73	21.2	1.76
Queensland	21	2	23	6.7	0.90
Western Australia	10	0	10	2.9	0.70
South Australia	9	1	10	2.9	0.73
Tasmania	1	1	2	0.6	0.45
Northern Territory	0	0	0	0.0	0.00
Australian Capital Territory	3	0	3	0.9	1.16
Australia	329	16	345	100.0	2.15

Source: NHMRC Special Unit in AIDS Epidemiology and Clinical Research 1988.

The heavy concentration of AIDS cases in New South Wales, and especially in inner metropolitan Sydney, may be explained both historically and demographically. Sydney is the main point of entry into Australia and has a larger number of homosexual men than other cities or areas. The current geographic case distribution of reported AIDS cases, with epicentres in Sydney and Melbourne, largely indicates the earlier distribution and spread of HIV.

HIV-related illnesses have been predominantly reported in urban areas in Australia. This is true of sexually transmitted diseases as a whole. In Victoria, with three metropolitan and five country regions, 96 per cent of 127 reported AIDS cases as at 31 December 1987 had been diagnosed in the three urban regions of south east metropolitan (57.5 per cent), western metropolitan (22.8 per cent) and north east metropolitan (15.7 per cent). Only 3.9 per cent occurred in the five country regions. Although the reported AIDS cases in Victoria were concentrated in the areas closer to the inner city, cases were also reported from a wide range of outer suburban areas.

1.1.4 Predicting the spread of AIDS

Short-term projections of the number of AIDS cases in the next three to five years can be made using curve-fitting techniques. Such methods are based on the set of currently reported cases of AIDS by year of diagnosis and therefore provide predictions of cases by year of diagnosis.

Most cases currently diagnosed are probably not a result of recent infection. If no future infections were to occur, projections, in the short term, would give similar results.

Table 3 shows the projected annual incidence of reported AIDS cases and the cumulative number of cases in Australia from 1988 to 1990. The projections suggest that there could be over 1000 cases of AIDS diagnosed during 1990, and that by the end of 1990 over 3000 cases of AIDS may have been diagnosed since the virus entered Australia. Other projections based on different assumptions have predicted more conservative growth than indicated here. Because of delays in reporting, it is not possible to make projections on the basis of the numbers of cases that have been reported as diagnosed in recent months.

Table 3:

Projection of incidence of AIDS cases, Australia, 1988 to 1990

	1988	1989	1990
Annual incidence	545	780	1060
Cumulative total at end of year	1270	2050	3110

Source: NHMRC Special Unit in AIDS Epidemiology and Clinical Research 1988.

Although there is evidence of a decreased or stable incidence of new infections among homosexual men in Sydney and Melbourne, because of the size of the homosexual population at risk many new infections will occur in this group in the next four years. New infections among needle sharing drug users, both men and women, may increase rapidly, and infected drug users could pass on the infection to their sexual partners and perinatally to their children.

Infection levels in women who work as prostitutes in Australia are low and should continue to remain low among those who are not intravenous drug users. Men who work as prostitutes, their partners and their clients are at higher risk of new infections, particularly where the prostitutes are also intravenous drug users.

There is not enough information to predict the future incidence of HIV infection through heterosexual transmission, but the present low numbers are likely to increase over the next few years.

There are many reasons why it is not possible to make adequate predictions. There have been no previous retrovirus infections in humans to provide comparisons, nor can the impact of treatment measures be adequately assessed at this stage. The knowledge of sexual and drug taking behaviour in our society is inadequate. These are difficult areas to research, but the need for more knowledge is pressing.

The accuracy of projections could be increased if more was known about the pattern and trends of infection, by age, sex and mode of transmission, about the progression of the disease, about HIV infectivity, and about cofactors.

1.2 Transmission of the Human Immunodeficiency Virus

Epidemiological studies in Australia, the Americas, Europe and Africa have documented three modes of HIV transmission: sexual; perinatal, that is, transmission from mother to child in the womb, while breastfeeding or, possibly, during birth; and contact with blood or blood products, donated organs or semen and some other body fluids.

The possibility of some previously unrecognised way of acquiring the virus cannot be entirely excluded but evidence strongly indicates that these are the only means.

Not all exposures to HIV, even contact with infected blood, will result in transmission; the virus must enter the blood of the exposed person.

1.2.1 Sexual transmission

A person is at risk of becoming infected with HIV if he or she has unprotected sexual intercourse, particularly unprotected anal or vaginal intercourse, with an HIV-infected person.

People are not at risk of sexual transmission of HIV if their partner is not infected. Where the HIV status of a sexual partner is unknown, the risk of transmission can be reduced or eliminated by the proper use of quality rubber condoms with water based lubricants for penetrative intercourse.

People who do not currently have any sexual contacts and who have not had any in the last seven or so years are not at risk of sexual transmission. Those in an exclusive relationship, such as a monogamous marriage, where both partners have remained faithful, and neither has received a blood transfusion or blood products since the virus entered Australia, are not at risk of sexual transmission. The risk status of a person who remains faithful to a single sexual partner is dependant on the other person's behaviour.

Epidemiological studies in Africa and the Caribbean indicate that transmission between heterosexuals may be more common worldwide than transmission between homosexuals [WHO 1987; Piot et al 1987; Friedland and Klein 1987; Piot et al 1984; Van de Perre et al 1985; Quinn et al 1986; Pape et al 1985].

Unprotected anal intercourse, both receptive and insertive, is a high risk behaviour for sexual transmission whether practised by homosexuals or heterosexuals.

Transmission can also occur through unprotected vaginal intercourse during which the virus may pass from an infected woman to a man or an infected man to a woman. HIV has been isolated from the semen of infected men and cervical and vaginal secretions of infected women. Genital tract shedding of HIV in women may occur at any stage throughout the menstrual cycle [Vogt et al 1986].

The first evidence of heterosexual transmission was reported in the United States in early 1983 [Harris et al 1983]. In the United States, 4 per cent of all adults with AIDS are reported as having become infected by heterosexual contact. Although this proportion is small, heterosexual transmission without any other risk factors is increasing more rapidly than other modes of transmission. The first reported AIDS case arising from heterosexual transmission in Australia occurred in October 1985.

Epidemiological data from Africa [Piot and Mann 1987] and a prospective study of spouses of AIDS patients [Fischl et al 1987] suggest that the efficacy of heterosexual transmission may be similar in each direction.

The presence of a sexually transmitted disease, or a history of them, can be interpreted as a marker of the kind of sexual activity that may put a person at risk. An association could be expected between high levels of sexually transmitted diseases and HIV infection.

The presence of a sexually transmitted disease may be a cofactor for HIV infection, that is, be directly involved in the cause of infection. There is some evidence that genital ulceration and other trauma to exposed surfaces may increase the likelihood of the sexual transmission. While genital ulceration due to syphilis or chancroid is uncommon in Australia, intermittent and recurrent genital ulceration due to *Herpes simplex* is extremely common. There is evidence that *Herpes simplex type 2* is a risk factor for HIV infection [Holmberg 1988].

Prospective studies of female prostitutes and their male clients in Nairobi show a much higher seroconversion rate among those with genital ulceration [Plummer et al 1987; Cameron et al 1987]. The latter study also shows a much higher risk of transmission from a single sexual contact than has been reported elsewhere.

In the Nairobi study the incidence of HIV infection was significantly higher in oral contraceptive users than in non-users. If this study was confirmed by further studies it would reinforce the importance of recommending condom use to women at risk of infection.

Any sexual practices which cause rectal or vaginal trauma may increase the risk of infection. The documented case of female to female transmission involved traumatic sexual contact [Marmor et al 1986]. However, a Sydney study of recipients of infected semen during artificial insemination shows

that exposure of the female cervical and vaginal lining to HIV is sufficient for transmission to occur [Stewart et al 1985].

There is no evidence that sexual activities such as kissing, digital contact and mutual masturbation carry any risk of transmission unless there is broken skin which could allow semen or blood to enter the bloodstream. However, infection in the receptive partner in orogenital intercourse has been reported [Mayer and DeGruttola 1987].

An important cofactor for both sexual and perinatal transmission of HIV may be the degree of virus expression or immuno-suppression in the infected partner [Goedert et al 1985]. Studies of sexual partners of infected people indicate that the risk of infection increases with the duration of infection. A study of perinatal transmission in Zaire found that the risk of transplacental transmission to the foetus varied inversely with T4+ cell levels [Nzila Nzilambi et al 1987]. These studies and others suggest that an HIV-infected individual's infectivity varies during infection. It is possible that infectivity is high during the initial acute infection stage and then decreases, rising again with a lowering of T4+ cell counts and with progression of HIV-related illnesses.

Number of sexual partners is often reported as a risk factor for sexual transmission. However, this only reflects the fact that the chance of meeting an infected partner increases as the number of partners increases. Limiting the number of sexual contacts may lower the risk of infection if the limiting can be combined with choosing sexual partners less likely to be infected [Hearst and Hulley 1988].

The risk of sexual transmission can be significantly lessened by the correct use of condoms. Rubber condoms have been shown to prevent the passage of *Herpes simplex, cytomegalovirus* and HIV in a series of small *in vitro* studies [Conant et al 1984; Conant et al 1986]. In actual use, infection may occur because of breakage or incorrect condom use, such as the use of oil based rather than water based lubricants. The frequency of the various causes of condom failure is not known. Natural membrane condoms have been shown to be ineffective in preventing the passage of hepatitis B virus and HIV [Minuk et al 1987; Van de Perre et al 1987].

Data on the effectiveness of condoms to prevent pregnancies cannot be used to indicate condom effectiveness in preventing HIV infection. This is partly because HIV infection can occur at any time, but pregnancy can occur only at ovulation. Further, the efficacy of condoms is dependent on their quality and the motivation of the couple using them. The protective effect of condoms can be significantly increased through education for correct use and through strictly applied quality standards and control.

A number of in vitro studies, including simulated condom rupture and spillage, have been conducted and indicate that the commonly used spermicide nonoxynol-9 can inactivate HIV in low concentrations [Hicks

et al 1985; Rietmeijer et al 1988]. This suggests that risk of HIV transmission could be reduced by the external application of spermicide with or without a condom, or by using condoms which have been specially treated with spermicides. However, evidence of the efficacy of nonoxynol-9 in inactivating HIV *in vivo* is not conclusive [Kreiss et al 1988].

1.2.2 Perinatal transmission

A woman is at risk of transmitting the virus to her child if she becomes pregnant when infected or becomes infected during pregnancy or while breast feeding.

The virus has been isolated from the placenta and the amniotic fluid, from the foetus between the 12th to 16th week of gestation, from cervical secretions, from cord blood and from breast milk.

Transmission from infected women to their children may occur through the placenta to the foetus, to the infant after birth through infected breast milk and, possibly, to the infant during labour and delivery, for example, through the ingestion of blood and other infected fluids. The relative efficiency and frequency of each route is unknown. An infant may be infected through one, some or all of these modes of transmission. Only intra-uterine and postnatal transmission have been documented.

A recent survey in New York City showed that one in 61 babies born were HIV-infected, and in some parts of New York City, the rate was as high as one in 41. The demographic features of paediatric HIV infection are similar to those of infected women. In the United States, black and Hispanic children are disproportionately infected.

The rate of perinatal transmission is not known. Diagnosis is problematic since antibodies to viruses are transferred from a mother to her child *in utero*. These passively acquired antibodies can remain in a child's bloodstream for many months after birth. The blood test used to diagnose HIV infection is a test for antibodies and is of uncertain value in children of HIV-infected mothers during the first months of life. Supplementary tests which are more specific for the paediatric population need to be developed.

Studies of children born to known seropositive women reveal a wide range of rates of infant infection, from zero to 65 per cent. Most studies indicate that the risk of transmission to infants is in the range of 30 to 65 per cent. Women who bear an infected infant may subsequently bear an uninfected infant. Risk of transmission increases if the mother is in the later stages of infection or if the mother is infected during the pregnancy.

HIV is known to be present in the milk of infected women. Nine Australian mothers have been infected with HIV after giving birth to their babies and all breastfed for up to three months after becoming infected. Three of these

breastfed infants have also become infected with HIV and it must be considered that a possible route of infection was via breast milk [Ziegler 1987]. Three babies in overseas studies are believed to have been infected in the same way [Weinbreck et al 1988; Lepage et al 1987]. As a result of these reports health authorities have warned of the potential for transmission of HIV from infected mother to infant during breastfeeding.

The extent of HIV infection in women of child-bearing age in Australia is low. However, cases of perinatal transmission have already occurred; 14 infants have been born to mothers who were infected before the birth; seven breastfed and seven did not. Two children in each group have been found to have been infected. The risk of transmission from mother to infant appears to be little altered by breastfeeding although it may be higher if the mother acquires the infection after delivery [Ziegler 1988].

Breast milk banking is an established method for providing high-risk neonates with breast milk. The possibility of transmission of HIV in breast milk has led to the review of current banking procedures. Pasteurisation is the method most frequently used to minimise contamination. Additional methods to protect the milk supplied to breast milk banks should include selection of donors who appear healthy and who use hygienic methods for expressing milk. Screening of donors should include questions regarding risk factors for HIV and consideration should be given to the HIV testing of breast milk donors.

1.2.3 Transmission by blood

This mode of transmission can occur in three different contexts: through equipment sharing in drug use; through transfusion of whole blood, blood products or transplantation of human tissue; and through occupational exposure to body fluids or accidental injection.

Transmission through equipment sharing in drug use

Intravenous drug users risk infection with HIV if they share needles, syringes or any other equipment used for preparing or injecting drugs with a person who is infected with HIV.

Experience in a number of areas in England and in the Netherlands indicates that the rate of HIV infection can be kept low through needle and syringe exchange programs, drug dependency clinics, treatment programs and social help and support services.

In several European cities where such programs have not been instituted, studies have shown that the HIV prevalence rates among intravenous drug users have increased rapidly: in Milan from 0.7 per cent to 35 per cent in six years [Ferroni et al 1985]; in Geneva from 7 per cent to 52 per cent in four years [Hirschel et al 1986]; and, in Edinburgh from 0 per cent to 51 per cent in two years [Scottish Home and Health Department 1986].

In the United States, 25 per cent of all reported AIDS cases have occurred in people who use drugs intravenously and 17 per cent have occurred among those for whom intravenous drug use is the only risk factor. Intravenous drug users now account for over half of the new reported cases of AIDS in New York, New Jersey and Connecticut.

Over half of the reported AIDS cases in women in the United States (53 per cent) were intravenous drug users, and 22 per cent of the remaining women are or have been the sexual partners of intravenous drug users [Weinberg and Murray 1987]. Fifty four per cent of paediatric AIDS cases in the United States are children born to these women. In New York City, 80 per cent of paediatric AIDS cases are children of such women.

In the United States and Europe, most intravenous drug users are heterosexual and most are men. Many intravenous drug users, both male and female, engage regularly or occasionally in prostitution [Drucker 1986].

Data on intravenous drug use in Australia are less complete than overseas data but indicate a similar pattern. Recent studies have shown that a number of Sydney intravenous drug users are HIV infected [Wodak et al 1987]. It is possible that seroprevalence among these intravenous drug users is between 1 and 1.5 per cent [Wodak 1988]. Wodak and Gold [1987] estimate the proportion of women intravenous drug users in Sydney who work as prostitutes at about 40 per cent. A significant number of male intravenous drug users also engage in prostitution.

Research conducted in Australia [Edgoose and Baillie 1987; Whyte et al 1987] indicates that intravenous drug users engage in all behaviours, including sexual behaviour, which could place them at risk of infection and, in particular, they engage in high levels of needle and syringe sharing.

A number of forms of hepatitis are also spread by exchange of body fluids. The presence of hepatitis B markers indicates a high risk of HIV infection. Prevention of the spread of hepatitis among intravenous drug users also depends on minimising needle sharing.

Transmission through blood transfusion, blood products or human tissue

A person is at high risk of becoming infected with HIV if he or she receives whole blood, cellular components of blood, plasma, certain infected other blood products, or tissue of an infected person. Immunoglobulin, albumin, hepatitis B vaccine and plasma protein fraction have not been implicated in HIV transmission.

To 11 October 1988, around 6 per cent of people with AIDS in Australia are believed to have become infected by exposure to blood or blood products before mid 1985. Of all reported AIDS cases to that date, 4.7 per cent (48) occurred among recipients of blood transfusions and 1.3 per cent (13) among recipients of blood products. It is possible that there is a higher rate of

underreporting of AIDS cases in these groups than in other groups. Further cases of AIDS as a result of such exposure will occur in the next few years among those currently so infected.

This route of HIV tranmission has been almost completely eliminated. The testing of blood donations has been complemented by self-exclusion of people at risk. Donor declarations relating to risk behaviour are reinforced by legislation.

All donors of organs for transplant use and semen for artificial insemination are tested for the presence of HIV antibody. This testing is also complemented by the self-exclusion of people at risk.

Transmission through occupational exposure to body fluids or through injection

A person is at risk of becoming infected if HIV-infected blood is injected into the body or comes into contact with open skin lesions or mucous membranes.

Transmission through significant occupational injuries has been reported in a small number of cases. However, the extremely low incidence of hospital or laboratory acquired HIV infection indicates that unbroken skin is an effective barrier to transmission.

Studies of accidental occupational injuries indicate that the injection of a single small amount of infected blood carries a very low risk of infection. The rate of HIV infection is about 0.4 per cent for all documented skin puncture or mucous membrane exposures. The risk of hepatitis B infection through accidental needlestick injuries from patients positive for hepatitis B surface antigen ranges from 10 to 20 per cent.

The distribution of occupational infection among health care workers, by occupation, in several overseas countries, is shown in **Table 4** below. In each case the source of infection was a patient known to be infected.

Forty per cent of the occupational injuries and two out of the three mucous membrane exposures resulting in HIV infection may have been prevented if existing infection control guidelines had been followed [Friedland and Klein 1987]. Failure on the part of health care workers to observe infection control guidelines, and the institution of elaborate precautionary procedures different from the established routines, both increase the risk of HIV infection.

In two cases, transmission occurred in home care settings. In one of those, a mother was caring for her infected infant; in the other, a woman was caring for her sick neighbour. In neither case were any precautions taken to prevent transmission [Grint and McEvoy, 1985; CDC 1987b].

Table 4:

HIV-infected health care workers with no reported non-occupational risk factors and for whom case histories have been documented in the scientific literature

Case	Occupation	Country	Type of Exposure	Source
1	Not specified	United States	Needlestick	AIDS patient
2	Not specified	United States	Needlestick	AIDS patient
3	Not specified	United States	Needlestick	AIDS patient
4	Not specified	United States	2 Needlesticks	AIDS patient, HIV-infected patient
5	Not specified	United States	Needlestick	AIDS patient
6	Nurse	England	Needlestick	AIDS patient
7	Nurse	France	Needlestick	HIV-infected patient
8	Nurse	Martinique	Needlestick	AIDS patient
9	Research Lab Worker	United States	Cut with sharp object	Concentrated virus
10	Home health-care provider	United States	Cutaneous (a)	AIDS patient
11	Not specified	United States	Nonintact skin	AIDS patient
12	Phlebotomist	United States	Mucous membrane	HIV-infected patient
13	Technologist	United States	Nonintact skin	HIV-infected patient
14	Not specified	United States	Needlestick	AIDS patient
15	Nurse	Italy	Mucous membrane	HIV-infected patient

(a) Mother who provided nursing care for her child with HIV infection; extensive contact with the child's blood and body secretions and excretions occurred; the mother did not wear gloves and often did not wash her hands immediately after exposure.

Source: CDC, 1988

1.2.4 Modes which have not been implicated in transmission

Virtually all known cases of HIV infection may be attributed to one or other of the established modes of transmission. There are no documented cases of transmission via casual, non-sexual social contact, of transmission in occupational settings other than health care settings, of transmission by insects or other vectors, or of transmission through the common use of facilities such as swimming pools, eating utensils, communion cups or toilets.

Insect transmission

There is no evidence of insect transmission of HIV. Data globally show that both HIV infection and illness are age-specific and, in some areas, sex-specific. Insect borne transmission would put all people at risk, whatever the age or sex. In African urban areas where children and the aged spend most of their time outdoors, prevalence figures would be significantly higher in these age groups if transmission occurred through insect bites. Serological testing has shown that HIV-infected people are not more likely than others to have been exposed to insect borne diseases.

Social or non-sexual household contact

A significant number of studies have been undertaken of households where one or more members were infected with HIV. The infected members have included intravenous drug users, people with haemophilia, homosexual and bisexual men, recipients of blood transfusions and heterosexual men and women. Not a single case of infection has been reported in other household members except where these members had been additionally exposed to the virus through blood, sexual activity or perinatal transmission.

In many of these studies, no specific precautions against household transmission were taken since the infection status of the member was not yet diagnosed. Contact between members included shared household facilities including beds, toilets, bathroom facilities, kitchens and household items such as towels, sheets, crockery, cutlery and glasses. Clothing was washed together in many households. Hugging and kissing on the cheeks and lips frequently occurred. In one study, occasional biting of siblings by infected children occurred [Rogers et al 1986]. In spite of closeness of the contact over prolonged periods, at times until death, none of the household contacts had evidence of infection through these means. In one reported case, an adult HIV-infected patient bit 30 health care workers without resultant HIV transmission [Tsoukas et al 1986].

Body fluids

HIV has been isolated from most body fluids although only blood, semen and breast milk have been implicated in transmission. It is likely that transmission by vaginal and cervical secretions occur. However, the possibility of transmission by body fluids, including by saliva, continues to be of concern to the general community. In the household studies, such transmission was shown not to have occurred. There is now evidence which indicates that HIV replication is inhibited in the presence of saliva [Fultz 1986].

1.2.5 Conclusion

Accumulated evidence indicates that transmission occurs only through blood, certain sexual activities and perinatally. However, fear of transmission by other routes continues and must be acknowledged and addressed as part of the psychological setting of the epidemic. The virus spreads because of personal and cultural patterns of behaviour, in particular sexual and needle sharing behaviour, rather than through social contacts.

Public attention on non-proven and unlikely modes of transmission makes the formulation of rational public policy more difficult. Public preparedness to look at actual modes of transmission is essential.

1.3 Clinical manifestations and natural history of HIV infection

The following description of the clinical manifestations and natural history of HIV infection is based largely on Australian data, with overseas data discussed where relevant or where Australian data are not available. Australian research so far indicates that there do not appear to be significant differences in this country compared with other developed nations.

1.3.1 Natural history of infection with HIV

There is generally a long latent period between initial HIV infection and the development of severe HIV-related illnesses. Determination of the maximum possible time between initial infection and serious progression is at present limited by the period we have been observing the disease. It is not known what percentage of infected people will progress to AIDS.

Overseas studies, mainly in the United States, have shown that 10 to 15 per cent of HIV-infected people who are symptomless will develop severe life-threatening HIV-related illness within three years of observation. During this period a further 35 to 45 per cent of asymptomatic subjects will develop less severe HIV-related illness. Additionally, once a person has developed one of these less severe HIV-related illnesses their risk of progressing to a life-threatening HIV-related illness increases to between 35 and 70 per cent within three years [Mathur-Wagh et al 1985; Goedert et al 1986; Goedert et al 1987; Polk et al 1987].

In Australia, studies of homosexual men have indicated that over a period of three years approximately 8 to 10 per cent of infected homosexual men have developed severe life-threatening HIV-related illness.

In the Sydney AIDS Prospective Study, between 3 and 4 per cent of HIV-infected subjects developed AIDS each year [Tindall and Cooper 1988c]. As with overseas studies, this study found that homosexual men who had an HIV-related illness or a low number of T4+ cells had the highest rate of progression. In the Melbourne-based cohort study [Mulhall et al 1988], 10 per cent of seropositive subjects developed life-threatening HIV-related illness over three years.

It is not yet known whether people who have remained well over years of observation will continue to do so. Some authorities believe that the principal determinant of the development of AIDS is the passage of time, with an increasing proportion of those infected becoming ill as time

progresses. There is no evidence that people can become immune to HIV, neither is there evidence that all infected people will develop severe disease.

Behavioural, environmental and genetic differences may play a role in determining which HIV-infected people will progress to severe HIV-related illnesses. Cofactors which may adversely affect the immune system or reactivate latent viral infection include repeated exposure to HIV and semen, recurrent sexually transmissible diseases, drug use, excessive alcohol ingestion, poor nutrition, stress and inadequate rest.

1.3.2 Infection with HIV

Although the conditions known as AIDS have received most publicity in the medical and lay press, people infected with HIV may be symptomless or develop a wide range of other illnesses. It is impossible to tell that a person has HIV infection from physical appearance alone.

HIV selectively infects and destroys an integral part of the human immune system: the white blood cells called T4+ lymphocytes.

After HIV infection, there is generally a decrease over time in the number and function of T4+ cells and the body becomes increasingly susceptible to various other infections, some of which rarely cause illness in people not infected with HIV. When the level of T4+ cells becomes critically low, the body becomes susceptible to severe life-threatening opportunistic infections and cancers.

HIV has also been identified in some cells of the gastrointestinal tract [Nelson et al 1988], in the retina, and in cells of the central and peripheral nervous system.

Acute HIV infection

One to three weeks after infection with HIV, between 50 and 90 per cent of people experience an acute illness [Tindall et al 1988b]. The symptoms resemble glandular fever and range from malaise to a variety of symptoms including fever, sweats, muscle or joint pains, lethargy, enlarged lymph glands, sore throat, loss of appetite, nausea, vomiting, headaches, abnormal intolerance of light, rash and diarrhoea [Tindall and Cooper 1988a]. Some or all of these symptoms may be experienced by any one person. Involvement of the nervous system during the period of acute infection, including encephalitis, meningitis, and inflammation of the spinal cord or peripheral nerves, has also been reported [Price et al 1988]. Depression and irritability are common [Tindall and Cooper 1988b].

This broad range of symptoms reflects the widespread dissemination of HIV throughout the body, including the nervous system, at this early stage.

The illness is usually sudden and lasts eight to eighteen days, but some people may experience recurrent intermittent symptoms for several weeks or months [Cooper et al 1985; Biggs et al 1986; Tindall and Cooper 1988a]. In one Australian study, 14 per cent of people who acquired the infection required hospitalisation for acute illness [Tindall and Cooper 1988b]. No deaths have been reported during this phase of infection.

Antibodies to HIV generally become detectable in the person's bloodstream between two and four weeks after the onset of the acute illness. In a small number of cases, they may take longer to appear. A positive result on an antibody test indicates only that the person has been infected with HIV. It does not indicate whether the person will eventually develop AIDS or other fatal illness due to the HIV infection.

Asymptomatic HIV infection

Following acute HIV infection, some people enter a stage in which they feel well and have no signs or symptoms of HIV infection, although HIV can still be isolated from their blood [Neate et al 1987]. During this period the person should be considered capable of transmitting the virus [Donovan et al 1986] and counselled accordingly. Although experiencing no symptoms, these people may have detectable abnormalities in their immune systems. In one study of homosexual men in Sydney, 45 per cent with asymptomatic infection had these abnormalities [Tindall et al 1986].

A recent study has suggested that neuropsychological abnormalities occur early in the course of HIV infection and possibly even in the absence of constitutional symptoms [Grant et al 1987]. However, other recent studies on larger samples indicate that such people do not have more neurological or neuropsychological abnormalities than uninfected people [Janssen et al 1988; Perdices 1988; Selnes et al 1988]. At present, there is no firm evidence that an infected individual without symptoms such as fever or weight loss will have more neurological or neuropsychiatric abnormalities than an uninfected individual.

Chronic meningitis can occur at any time in HIV infection.

HIV-related illnesses

Following infection with HIV, some patients experience a wide variety of symptoms and illnesses without having AIDS. These illnesses are more common in people with HIV infection who are immunodeficient [Donovan et al 1986].

Common manifestations at this stage of HIV infection include persistent enlargement of lymph glands, recurrent diarrhoea, weight loss, fevers, fatigue and recurrent bacterial, viral and fungal skin infections such as psoriasis or dermatitis [Dalgleish et al 1983; Smith et al 1983; Hill et al 1984; Donovan et al 1986]. These symptoms recur frequently [Lucas 1985].

Some people have detectable abnormalities in cognitive function [Perdices 1987]. Individuals may experience difficulty with short-term memory and learning, have reduced mental flexibility and have difficulty processing complex tasks. These effects are often subtle and may not impair ability to carry out everyday tasks [Perdices 1988].

Acquired Immune Deficiency Syndrome (AIDS)

Acquired Immune Deficiency Syndrome (AIDS) comprises the most severe manifestations of HIV infection.

The diagnosis of AIDS is only applied where the person has developed one of a series of specified life-threatening opportunistic infections or cancers. These diseases are typically severe, multiple, resistant to standard treatment, and recurrent. Additionally, AIDS may be diagnosed in a person with HIV infection who presents with a dementia known as HIV encephalopathy or AIDS Dementia Complex [CDC 1987a] or an HIV-related wasting syndrome.

Respiratory system. The respiratory system is frequently affected. In one Australian study, 59 per cent of hospitalised AIDS patients had respiratory disease. The most common of these is a pneumonia caused by the parasite *Pneumocystis carinii*. This infection can be treated with drugs, but there is a high incidence of side effects [Gibson et al 1987].

Another common respiratory manifestation in AIDS is pneumonia in which no specific infecting organism can be found. This disease has been referred to as lymphocytic interstitial pneumonitis or non-specific pneumonitis. It is especially common in children with AIDS. Many other organisms, including viruses, bacteria and fungi, have been shown to cause respiratory disease in AIDS patients. Tumors such as Kaposi's sarcoma and lymphoma can also develop in the lung.

The nervous system. Impairment of the nervous system can be caused by the direct action of HIV itself on the nervous system, or by HIV acting on cells of the immune system, resulting in opportunistic infections and tumors within the nervous system. Ten per cent of infected people present with a neurological symptom as their first sign of infection. Approximately 40 per cent develop neurological symptoms in the course of infection. Approximately 80 to 90 per cent show signs of changes in the central nervous system at autopsies [Levy et al. 1985; Price et al. 1986].

In some people, the mild cognitive impairment may progress and a dementia may develop over a period of months [Navia et al 1986]. Symptoms include slowing of speech and thought, impaired concentration and progressive memory loss. Impairment of motor function such as loss of coordination, leg weakness and tremor and changes in behaviour such as apathy, withdrawal and blunting of emotions are commonly associated. In its most severe form, the patient may be confused, incontinent, mute and bedridden. Coma may develop in the end stages. This constellation of

symptoms and signs is referred to as the AIDS Dementia Complex or HIV encephalopathy.

HIV may directly affect the spinal cord leading to a disorder known as vacuolar myelopathy in 10 to 20 percent of patients with AIDS. Pain, progressive weakness and lack of coordination of the legs are common. These symptoms may also occur because of inflammation of the peripheral nerves of the arms and legs [Gabuzda et al 1987; McArthur 1987].

The most common opportunistic infection involving the central nervous system in AIDS patients is caused by an organism called *Toxoplasma gondii*, which leads to lesions in the brain. Patients with this infection may develop headaches, changes in behaviour, confusion and convulsions [Buhrich and Cooper 1987; McArthur 1987].

Meningitis may develop and is usually caused by the fungus *Cryptococcus neoformans*. The person experiences headache and nausea, and may develop changes in behaviour and personality [Gabuzda et al 1987]. Lymphoma of the central nervous system occurs in approximately 10 per cent of AIDS patients. Common symptoms are altered mental states and headache, which may progress over a period of weeks before the person seeks medical attention. This clinical manifestation is resistant to treatment and the prognosis for such people is poor [Herman 1986; McArthur 1987]. Kaposi's sarcoma may also develop in the nervous system, but this is rare. In one Australian study, 77 per cent of AIDS patients had some degree of visual disturbance [Woods et al 1986]. Progressive blindness in patients with AIDS is caused by infection of the retina with *cytomegalovirus*.

The gastrointestinal system. Weight loss almost inevitably occurs in people with AIDS [Dworkin et al 1985]. This can be caused by chronic diarrhoea, by lymphoma, by any severe opportunistic infection, loss of appetite or nausea from drug treatment. The loss may be profound and rapid.

Diarrhoea is present in 55 to 60 per cent of AIDS patients and is frequently severe and incapacitating [Dworkin et al 1985; Gelb et al 1986]. The diarrhoea may be caused by a variety of organisms but in approximately 40 per cent of AIDS patients with diarrhoea no causative organism is found [Gelb et al 1986].

Diarrhoea in AIDS patients requires extensive investigation [Ralston et al 1987] and is difficult to manage. Nutritional depletion is often associated with the diarrhoea.

Thrush of the mouth is common and may extend into the oesophagus, causing inflammation and severe pain on swallowing. These symptoms may also develop with severe *Herpes simplex* lesions. Homosexual men with AIDS can suffer from extremely painful chronic ulceration of the anal region due to reactivation of *Herpes simplex* virus infection.

Tumors. Kaposi's sarcoma is the most common tumor in AIDS. In the advanced stages, the skin lesions may be very disfiguring. It usually presents as painless red-purple lesions on the skin but can also affect lymph glands, gastrointestinal tract, lungs and nervous system, even in the absence of skin lesions [Fisher et al 1987; Smith et al 1987; Barrison et al 1988].

Lymphoma is a tumor of lymphoid tissue which may affect lymph glands, the central nervous system, bone marrow, or the gastrointestinal tract. Fever and weight loss are common symptoms. Lymphomas in people with HIV infection do not respond well to therapy, and relapse occurs early. The immunodeficiency of HIV infection may also predispose patients to other cancers including basal cell carcinomas and malignant melanomas [Fisher et al 1987; Tindall and Cooper 1988d].

Psychological and psychiatric manifestations

A person diagnosed as having HIV infection is faced with the possibility of a prolonged and often fatal illness. As a result, he or she will become dependent on others at least at some stage of the illness. Most patients will eventually have to give up their work because of ill health.

Many individuals may have to reveal themselves to family members as homosexuals or intravenous drug users and cope with the reactions this elicits.

HIV-related illnesses can have an effect on a person's physical appearance, leading to reduced self-esteem. These, and other problems, place enormous stress on a person. Anxiety and depression are likely, requiring counselling and supportive measures.

Patients may experience several psychological reactions to the diagnosis [Ross 1985; Anns 1987a]. These include feelings of powerlessness, shock, isolation, anger, denial, guilt, anxiety, fear and apathy. Depression and withdrawal may occur, making it difficult to function at work or socially [Buhrich and Cooper 1987; Fenton 1987; Buhrich 1988]. In some patients severe or chronic depression may increase the risk of suicide [Whiteford et al 1986; Buhrich 1988].

It is uncommon for people with HIV-related illnesses to require hospitalisation purely on the basis of a psychological disorder or intellectual impairment, although HIV infection may occur in people with a pre-existing psychiatric condition [Buhrich 1985].

AIDS in children. The presentation of AIDS in children is different from that in adults. The most common is a failure to thrive.

A newborn child has not had the opportunity to develop defences against common infections. The child may suffer from bacterial pneumonia, meningitis or septicaemia. Lymphocytic interstitial pneumonia is especially

common in children, occurring in up to 50 per cent of paediatric AIDS patients [Ziegler 1987].

Neurological damage due to direct effects of HIV may be more common and severe in children than in adults, and occurs during a period of neurological growth which is thus impeded. In young children, this damage causes loss of developmental milestones, intellectual deficits, weakness, coordination difficulty and convulsions [Epstein et al 1986]. Progressive encephalopathy in older children manifests as decreasing performance in school.

The average period of time between infection with HIV and the development of AIDS is shorter in children than in adults [Cowan et al 1985; Rogers et al 1987]. The survival time between diagnosis of AIDS and death is also shorter [Rogers et al 1987].

1.4 Behaviour change in response to the epidemic

The early recognition that the risk of HIV infection would be eliminated only as individuals changed their sexual or needle sharing behaviour resulted in intense efforts to bring about the necessary changes among people at risk of infection.

These efforts were begun by gay community organisations, often with the help of health workers. Soon after, government agencies, universities and trade unions became involved. More recently, collectives of prostitutes in Sydney, Melbourne and Perth, representing both males and females, have undertaken a similar role.

Initiatives for needle sharing drug users were slower, and came mainly from workers in government and non-government agencies rather than from intravenous drug users themselves. This is beginning to change in some places as individual users and ex-users are developing community based organisations.

Efforts to change the behaviour of heterosexual men and women have been slower. The small number of heterosexually acquired cases of AIDS has led to resistance to the idea that heterosexuals are, in fact, at risk. The most extensive programs so far have been carried out in schools. All States and Territories have initiated HIV education programs in schools, usually at all levels of the school system.

1.4.1 Evidence of behavour change

Behaviour change in homosexual or bisexual men

The gay community's existing communication networks, venues, community organisations, the gay media and health care providers have brought about behaviour change among homosexual or bisexual men. In some places, mass media and other forms of public communication have assisted. Increasingly, small-group work and other forms of peer education have developed.

By 1988, evidence from both Sydney and Melbourne indicated that the incidence of receptive anal intercourse had dropped markedly and was still falling. The reduction of sexually-transmitted diseases previously common among homosexual and bisexual men, particularly anal gonorrhoea, reflects the change [Donovan 1988; Tapsall et al 1988].

Data from the Social Aspects of the Prevention of AIDS, Study A, show there is a widespread awareness of the dangers posed by particular sexual behaviour, although there is uncertainty about the risk of practices other than anal intercourse. More than half the men interviewed had reduced their number of sexual partners and sexual contacts and more than half were more careful in their choice of partner. A significant shift was reported towards sexual practices which were promoted as safer [Connell et al 1988]. These findings are supported by other research carried out in Australia [Anns 1987b; Baxter et al 1987a; Kippax et al 1987; Ross 1987a; Sinnot and Todd 1987; McCamish 1987; Tindall and Cooper 1987]. It remains to be seen whether these changes are adequate to eliminate risk, and can be sustained over longer periods of time than have yet been studied.

The Sydney AIDS Project Study of 1 000 homosexual and bisexual men has revealed that the rate of new infections in men in this group has decreased since late 1985. The incidence of seroconversion was 1 per cent during 1984, 4 per cent during 1985, 2 per cent during 1986 and 1 per cent in 1987. Compared with seronegative men, seroconverters had more male sexual partners, were more likely to practice receptive anal intercourse and were more likely to have used drugs casually [Tindall and Cooper 1988c].

A Melbourne study of 100 asymptomatic homosexual men begun in 1983 showed that the prevalence of antibody to HIV rose from 22 per cent in 1983 to 31 per cent in 1985. Since then there have been no further seroconversions [Mulhall et al 1988]. Overseas studies report similar results [Hessol et al 1988; Detels et al 1988].

Behaviour change in other groups at risk of HIV infection

There is less direct evidence available for assessing relevant changes in behaviour for groups outside the homosexual community. No studies have been done in the general heterosexual population. However, among groups at higher risk of infection, such as intravenous drug users, female prostitutes and other people who attend STD clinics, there are indications that significant behaviour change has occurred.

Research studies are now underway in several centres to examine behaviour changes among intravenous drug users. Preliminary data from research at a Sydney detoxification hospital indicate encouraging falls in self-reported needle sharing practices. In February 1987, over 70 per cent of intravenous drug users admitted to the clinic reported regular needle sharing. This dropped to 40 per cent in July 1988. However, less than 1 per cent reported using condoms on a regular basis.

There is also evidence of significant behaviour changes by female prostitutes. Safe houses have been established in Melbourne and Sydney at which only safer sexual practices are offered. The combined efforts of the prostitutes, the Australian Prostitutes' Collective, STD clinic staff and general practitioners have led to a marked increase in the use of condoms

and a sharp decline in sexually transmitted diseases, particularly gonorrhoea [Donovan 1988].

Surveys of female prostitutes at the Sydney STD clinic have shown that the percentage using condoms with all their clients had increased to around 70 per cent by 1988 from levels of around 1 to 5 per cent in 1985 [Harcourt et al 1988].

Gonorrhoea notifications of heterosexual men and women by the Taylor Square Clinic in Sydney have steadily fallen from 173 in 1982 to 18 in 1987. This continuing decrease indicates a reduction in the number of sexual partners [Donovan 1988].

1.4.2 Factors influencing behaviour change

Risk behaviour is individual and private, is motivated by strong desires and reinforced by strongly entrenched group behaviour patterns. When developing policies and programs designed to encourage behaviour change, it is important to know the factors which influence such change.

Researchers and educators have identified a number of factors and characteristics that have influenced, positively or negatively, the speed with which homosexual and bisexual men responded to HIV education campaigns and moved away from risk behaviour [Connell 1987; Crooks 1987; Dowsett et al 1987; Ross 1987b; Tindall and Cooper 1988c]. In many cases several of these factors may overlap and reinforce each other.

The first factor, which influences behaviour positively, is direct knowledge of someone who is sick or who has died as a result of HIV infection. Knowledge of a partner, family member, friend or acquaintance who has become infected is a powerful force in bringing about personal recognition of risk and in influencing behaviour change. This is particularly likely to be so if a person knows someone who was infected as a result of unsafe behaviour which they themselves practise.

Second is negative external or environmental barriers. These are primarily legislative barriers which militate against the practice of safer behaviours and may discourage people in particular groups from approaching governments or health services. They include laws which limit or proscribe the availability of sterile equipment for intravenous drug use, laws against prostitution or male homosexuality, and regulations or social pressures which limit the sale, distribution and use of condoms.

The third factor is the use of alcohol and other drugs in sexual and pre-sexual situations. Alcohol and other drugs play an important part in the lives of many homosexual and bisexual men, and their effects may determine whether these men can adopt safer sexual practices [Carr 1988a; Stall et al 1986].

The physical effects of alcohol and other drugs are commonly believed to weaken self-control and the ability to stick to previous decisions to avoid risky behaviour. Recent Australian evidence, involving study groups of gay men who acknowledged engaging in unsafe sex while under the influence of alcohol and other drugs, suggests that this might not always be the cause [Carr 1988a]. It is argued that, for some homosexual and bisexual men, alcohol and other drugs may be used purposely to provide an excuse for unsafe sexual activity from which they derive social identity and validation.

Young homosexual and bisexual men who are using drugs may turn to prostitution to pay for the drug. The risk factors of youthfulness, intravenous drug use, and lack of involvement with the gay community result in a number of individuals who are particularly difficult to reach and to motivate to make sustained behaviour changes.

The fourth factor is relationship status. McKusick and Coates [1985] and, in Australia, McCamish [1987] and Connell et al [1988] reported that homosexual men in primary relationships were more likely to engage in sexual practices carrying a high risk of HIV infection with their primary partners than they were with other sexual partners. Also, they were slower to adopt safer sex practices with their primary partner than with others.

Several explanations have been given for this. One is that homosexual and bisexual men having sex with many different partners, and who identified with the warnings to promiscuous homosexual men, accepted early in the epidemic that they were at high risk of HIV infection and moved to safer sexual practices, while men who considered themselves non-promiscuous did not.

It may be that negotiating safer sex is harder with a regular partner than it is with casual partners. It may be also that the ideology of love creates a situation in which people are prepared to accept risks with their regular partner.

Research from the Langton Clinic study demonstrates that intravenous drug users do not count needle sharing episodes with sexual partners as holding the same risk for HIV transmission as sharing with other friends or strangers and so do not insist on using sterile or cleaned equipment. Many intravenous drug users insist on safer sexual practices when prostituting for money or for drugs, but not in their primary sexual relationship.

Overseas studies on HIV infection among prostitutes have shown a correlation between HIV infection and unprotected sexual relations with regular partners [Darrow 1988; Day 1988]. It is apparent that while condoms may be increasingly used with clients, people who work as prostitutes are not using them with their regular partners [Day 1988]. Anecdotal evidence suggests that this is because the use of condoms is associated with

professional protection, and not with trust and romantic love with a regular partner.

Unprotected sexual relations often continue between heterosexual couples in a stable relationship even when it is known that one is infected, or is at a high risk of being infected. This has been shown in studies involving people with haemophilia [eg Jason et al 1986]. The reasons for this may be the need to express support and closeness, and possibly the desire to have children.

The fifth factor is a group of psychosocial characteristics. This is one of the more elusive areas and difficult to quantify. It is also one of the most important since it has been known for some time that these factors influence behaviour, including health related behaviour change.

Ross and Gilbert [1987] compared personality criteria with the attitudes of homosexual and bisexual men in Adelaide to condom use. They found correlations between positive attitudes and personality characteristics such as dominance, autonomy and self-confidence, and negative correlations with abasement, deference and tension-anxiety.

Taken together with more extensive research overseas [Emmons et al 1986; Joseph et al 1987a; Joseph et al 1987b], these findings suggest that the most important psychosocial factors positively influencing behaviour change in homosexual and bisexual men are a positive self-image about sexual identity, a feeling of peer support from the gay community for changing behaviour, and confidence in the ability to make and sustain the change to safer sex practices. Factors negatively influencing behaviour change are the opposite of these: poor self-image, lack of confidence in behaviour change and ability to achieve it, and perceived lack of peer support for behaviour change.

The sixth factor is knowledge or lack of knowledge of HIV infection status. Knowledge of whether or not one is infected may have some effect on the speed and direction of behaviour change, particularly if accompanied by professional pre-test and post-test counselling [Joseph et al 1987a; McKusick et al 1985].

Homosexual or bisexual men who know that they are HIV-infected seem to make more rapid behaviour change than those who know that they are not infected, and those who do not know their infection status [Coates et al 1987; Fox et al 1987]. Homosexual and bisexual men who have been both tested and counselled show a higher rate of condom use and other forms of safer sexual practice than do either men who have only been counselled or men who have been neither tested nor counselled [Ross 1987a; Coates et al 1987]. However, knowledge that one is not HIV-infected, particularly where the testing occurred without adequate pre-test counselling, may retard or reverse behaviour change [Donovan 1988; Fox et al 1987].

Knowledge of HIV infection may produce negative psychological and behavioural changes, such as depression, alcohol and drug use and social isolation, which may adversely affect longer term ability to sustain change [Stall et al 1986; Emmons et al 1986; Joseph et al 1987a; Joseph et al 1987b].

It is possible that the degree to which a person identifies himself or herself as being at risk, and the factors which influence a person to choose to take the HIV antibody test, are both related to the likelihood of that person changing their behaviour after being tested.

The seventh factor is age. Both younger and, to a lesser extent, older homosexual and bisexual men have had more difficulty adapting to behaviour change than have men aged 25 to 45. Several reasons have been advanced.

Because most cases of HIV-related illness among homosexual and bisexual men have occurred among men aged 25 to 45, men outside this age bracket have less direct knowledge of the effects of such illness.

Younger homosexual and bisexual men, particularly those under 20, have in many cases a less well-developed sense of identity with the gay community, may be less accepting of themselves as homosexual men, and may have fewer opportunities to participate in gay community activities and develop relationships with other homosexual and bisexual men beyond the purely sexual. Younger homosexual or bisexual men may also lack the necessary experience and negotiating skills to be able always to insist on safer sexual practices.

Older homosexual and bisexual men formed their sexual identities and patterns of behaviour at a time when male homosexuality was stigmatised and repressed, and before the organised gay community of today came into existence. They often lack a strong self-image as homosexual men, are less accepting of their sexuality and less likely to take part in the activities in the gay community. Their sexual preferences and practices may be more deeply entrenched and resistant to change. In addition, older homosexual and bisexual men may be reluctant to adopt safer sexual practices from fear of rejection by potential sexual partners.

Almost all successful programs to change behaviour have been based on the following principles: personal recognition of risk of HIV infection; belief that recommended changes to behaviour will eliminate risk of infection; belief that one can make and sustain the changes to behaviour while not compromising enjoyment of life; and peer support.

Legislative, social and other barriers including lack of access to needles and syringes or condoms, must not impede the adoption of safer behaviour.

1.5 Cost and human resource implications of HIV

1.5.1 Introduction

Examining the economic consequences of any disease is important in formulating appropriate responses. Analysis of the overall cost in the context of available resources is needed to enable budgeting and to determine priorities for policy making. Estimating costs is essential for evaluating particular programs and strategies, and for comparing the relative advantages of different interventions.

Costs relating to HIV may be categorised according to whether they are program costs or case related costs. Program costs include expenditure on research, education and other preventive programs, blood screening and testing, training programs and administration. These costs have risen rapidly in the initial stages, but are largely independent of the number of people infected.

Case related costs may be broken down into direct costs, meaning expenditure on hospital clinical care, outpatient costs and special treatment; and indirect costs involving lost productivity and income arising from disablement and premature death. Case related expenditure will increase in line with the increasing number of HIV-related illnesses.

Two distinct approaches exist for measuring costs associated with HIV infection. For a given year, the prevalence approach identifies all case related expenditure which occurred as a result of HIV-related illness in that year, and also ascribes to that year the net present value of the forgone earnings of people who died of AIDS in that year. In contrast, the incidence approach records all costs which are attributable to infection which occurred in a particular year. This requires estimates of rates of progression to illness following infection, and a rate of discount to bring costs back to the year of initial infection.

Prevalence costings are easier to measure and are used to determine the extent to which current resources are taken up by HIV. Most costings have been done on this basis [Scitovsky and Rice 1987]. Incidence costs require much more detailed knowledge about the progression of infection and the epidemiology of HIV, and are relevant when assessing the potential benefits of preventive strategies.

1.5.2 Costing the epidemic

Existing costing studies in Australia have addressed only particular components of the total cost, or have defined the various components without being able to quantify them reliably. At this stage there are insufficient epidemiological data and estimates of various costs to enable such calculations. New patterns of care are evolving, brought about by rapidly growing skills and the need to spread scarce resources. New treatment drugs have been developed and are being tested.

Direct costs are incurred by both the public and private sectors. To date, most costs have been met by governments. Case related government outlays include expenditure on the hospital system, Medicare and the Pharmaceutical Benefit Scheme, special treatment costs and income support. Transfer payments such as income support do not form part of the true net cost to society, but are important from the point of view of resource allocation within a government's budget.

Private costs include privately funded education, care and prevention programs, research and life insurance. There are administrative and training costs involved in the mobilisation, training and support of significant numbers of volunteers for home care, emotional support, counselling and other community based support services. Most of these costs have been met by governments.

HIV costs in Australia will continue to grow as the prevalence of HIV-related illness increases. Even without further spread in the community, the progression of illness in those people already infected will have a major impact on our public and private health care systems.

Direct costs

Various attempts have been made to estimate case related expenditure on AIDS in Australia. Margaret Duckett [1987], building on the work of Whyte et al [1987], analysed the costs of care of 39 patients from St Vincent's hospital in Victoria, 23 patients at Fairfield in Victoria and 11 patients at Prince Henry in New South Wales. Bed-day cost calculations took into account the costs of additional dedicated staff working either wholly or partly with AIDS patients. The analysis did not include any assessment of capital costs, and treatment and investigational costs were separately identified, the latter being estimated by a proportion of the Medicare Schedule Fee.

This study showed an average annual total cost of hospital based treatment of $34 357 per patient, varying from $22 232 at St Vincent's to over $46 000 at Fairfield and Prince Henry. The average lifetime cost of hospital and home based treatment and care for a patient diagnosed as having AIDS was estimated to be $38 000.

In comparison, an earlier study by Phua and Goldstein [1985] estimated total hospital costs at $12 931 per patient in 1984/85 prices. However, this study

used average hospital bed day and outpatient visit costs for all patients, which would suggest that AIDS patients are considerably more expensive to treat than the average inpatient.

A major drawback with existing studies of the cost of care for HIV patients is that they were undertaken before the widespread use of treatment drugs, in particular AZT. The annual cost of providing AZT is around $10 000 per patient.

However, it is too early to assess the effect that treatment with AZT, or AZT in combination with other drugs, is likely to have on hospital costs. While the amelioration of symptoms may reduce the need for hospitalisation and major care in the short term, there is no evidence that existing treatments are more than a palliative or that they do more than postpone the onset of serious illness. The overall effect of treatment with drugs, with their associated side effects, may increase the average costs of hospitalisation.

Using a prevalence approach, a broad estimate of the direct cost of treatment of the four hundred to five hundred living AIDS patients in Australia in 1988 would be between $10m and $20m. The number of cases of HIV-related illnesses and their treatment costs, if average inpatient treatment costs are used, can be roughly estimated. The estimate of treatment costs in 1988 for AIDS and other HIV-related illnesses is around $25m to $50m.

Lack of sufficient data about the effects of treatment drugs, the costs of providing care in general and the numbers of people infected introduce large uncertainties into estimates of costs even for the present. Projections of costs in future years are more uncertain still.

Commonwealth expenditure

The first Commonwealth HIV-specific funding was announced in November 1984 at a special meeting of Australian Health Ministers. Over $5m was provided in direct grants to the States, $2.7m of which was for HIV screening of the blood banks. In March 1985 it was decided that additional costs to the public hospital system brought about by the increasing number of HIV infected people seeking treatment would be met through the existing Medicare Agreements.

Table 5 below sets out actual HIV expenditure from 1984–85 to 1987–88 and estimated expenditure for 1988–89 by the Commonwealth Department of Community Services and Health.

Table 5:

HIV-dedicated expenditure by the Commonwealth Department of Community Services and Health 1984–85 to 1988–89

($ million)

Categories	1984–85	1985–86	1986–87	1987–88	1988–89
Matched Funding Programs (a)					
Blood screening	2.67	1.97	1.95	2.72	2.83
Grants to States and Territories	1.03	3.95	3.99	6.51	10.00
Sub-total	3.70	5.92	5.94	9.23	12.83
National AIDS Program					
AIDS research	–	0.75	1.51	2.98	3.50
National education	0.57	0.34	2.90	3.63	3.80
National Reference Laboratory	0.29	0.36	0.48	0.62	0.79
Community projects	0.01	–	0.86	2.66	2.80
Information exchange	–	–	–	0.57	1.24
Other	0.49	0.45	–	0.34	0.39
Sub-total	1.36	1.91	5.75	10.79	12.52
Hospital-based treatment	–	–	–	1.00	15.12
TOTAL	5.06	7.84	11.68	21.02	40.46

(a) State and NT programs fully Commonwealth financed in 1984–85 and cost shared on 50:50 basis from 1985–86. ACT programs fully Commonwealth funded in 1984–85 and 1985–86, and cost shared 50:50 from 1986–87.

Source: Department of Community Services and Health 1988

Estimates of salary and administrative costs, Medicare, Pharmaceutical Benefits and other generic Department of Community Services and Health program expenditures attributable to HIV are not included, nor are any expenditures by other Commonwealth departments, authorities or instrumentalities.

Commonwealth HIV-dedicated expenditure rose by 55 per cent in 1985–86, 49 per cent in 1986–87, 80 per cent in 1987–88 and 92 per cent in 1988–89.

In recognition of the impact of AIDS on the State and Territory hospital systems, funding in 1988–89 by the Commonwealth includes $15.1 million under the revised Medicare Agreement which is to operate from 1 July 1988. This is an increase of $14.1 million over the Commonwealth's 1987–88 contribution for providing treatment to AIDS patients through the public hospital system. It will be indexed in line with the rest of the grant, and also for the increase in the number of AIDS cases.

Since 1987–88, the Commonwealth matching grants to the States and Territories have been allocated on the basis of notifications of AIDS cases, overall population and Aboriginal population. Commonwealth priorities for expenditure are reflected in the requirement that half of the amount is to be spent on prevention, education and counselling, and half on treatment and support services outside hospitals.

Within the amount spent on preventive education and counselling, between 10 and 35 per cent is to be spent on education and counselling and between 15 and 30 per cent on local community grants. Of the amount spent on treatment and support services outside hospitals, between 20 and 40 per cent is to be spent on clinical and support services for people with HIV-related illnesses who are not hospital inpatients and for diagnostic and antibody testing services, between 5 and 25 per cent on the development of an integrated domiciliary service package using community organisations, and between 5 and 25 per cent on coordination and evaluation.

Total government expenditure 1986–87

Touche Ross was commissioned in February 1988 by the Commonwealth Department of Community Services and Health to identify actual and projected costs associated with HIV infection in Australia and to determine the reliability of existing data on costs. The study was later expanded to include a preliminary description of the human resource requirements of HIV-related health and other services.

The Touche Ross study examined the availability of data for all types of resources related to HIV infection for the financial year 1986–87. It also sought to identify the key issues in human resource planning, including training and other support needs, and reasons for the reported high turnover.

Table 6 shows a summary of the data obtained for the Touche Ross study from sources throughout Australia. It has been subdivided into cost categories, and a notional completeness index has been included which estimates the proportion of the total costs identified in each category. While many of the main program related costs incurred by public authorities have been identified, the case related cost components are fairly meaningless at this stage, and significantly underestimate the true costs.

The relative importance of each main general program category is illustrated by **Figure 3**. It is notable that education programs, together with advertising and public relations, make up around 30 per cent of the total. Other major categories include blood transfusion service costs, at 16 per cent, and research at 9 per cent.

This preliminary costing study quantified HIV program costs at $27.3m in Australia for 1986–87, and case related costs at a significantly underreported level of $7.0m.

Figure 4 illustrates, for program expenditure only, the estimated increase in HIV-dedicated expenditure by individual State and Territory health authorities over the two years 1986/87 and 1987/88. Large increases can be seen in Queensland, Victoria, South Australia and New South Wales. Some of the increase can be attributed to changes in identifying expenditures already incurred, from general programs to HIV-dedicated programs.

Commonwealth and State government HIV-dedicated expenditure rose dramatically in 1987/88, the former by 80 per cent and by a further 92 per cent in 1988/89. Program expenditure is likely to continue to rise to meet increasing demands for education and prevention programs, for HIV blood testing and counselling and for research.

Indirect cost

The primary component of indirect cost is the forgone output of people who are removed from the workforce because of HIV infection. Using a human capital approach this is measured by prospective earnings lost. Indirect costs include morbidity and mortality costs of those directly infected with HIV, and costs arising from the time devoted by others to their care.

Table 6:

HIV-related costs summary, Australia, 1986–87

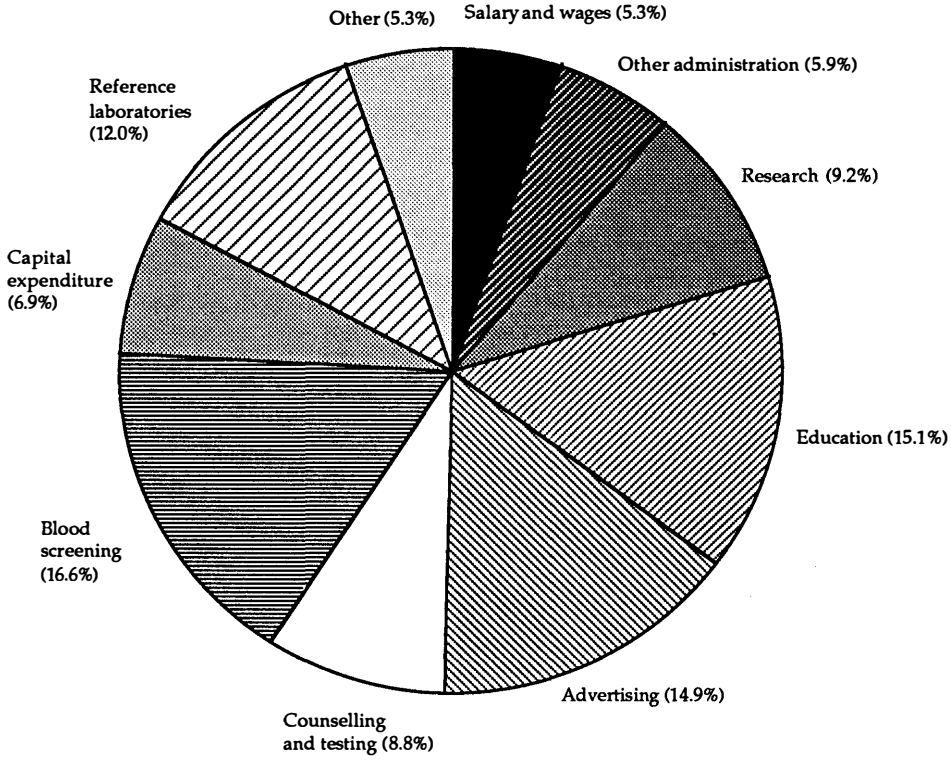
Service or program description	Expenditure ($'000)	Notional completeness index
Program Related:		
Administration		
Salary and wages	1 443	C
Other	1 601	C
International	10	B
Research	2 581	A
Education	4 099	B
Advertising/Public relations	4 054	B
Prevention	150	C
Special programs (AZT)	151	A
Counselling and testing	2 382	B
Testing blood donations	4 521	A
Securing the blood product supply	775	A
Training	252	C
Insurance	0	D
Capital expenditure	1 863	C
Information exchange	90	B
Reference laboratories	3 267	B
Other	13	C
Program expenditure	27 252	C
Case related:		
Medical		
Hospital	5 507	C
Non hospital	443	C
Social Security benefits	0	D
Veterans' Affairs benefits	0	D
Insurance/Superannuation benefits	0	D
Housing assistance	8	C
Government support services	1 068	C
Non government support services	18	C
Private costs	0	D
Work related costs	1	C
Capital expenditure	0	D
Concessions	0	D
Other	0	D
Case-related expenditure	7 045	C
Total	34 297	
Less grants accounted for elsewhere	(385)	
Total expenditure	33 912	C

A – Believed to include most of the relevant outlays.
C – Known to include only limited proportion of total costs.
B – Probably fairly incomplete.
D – No data available.

Source: Touche Ross 1988.

Figure 3:

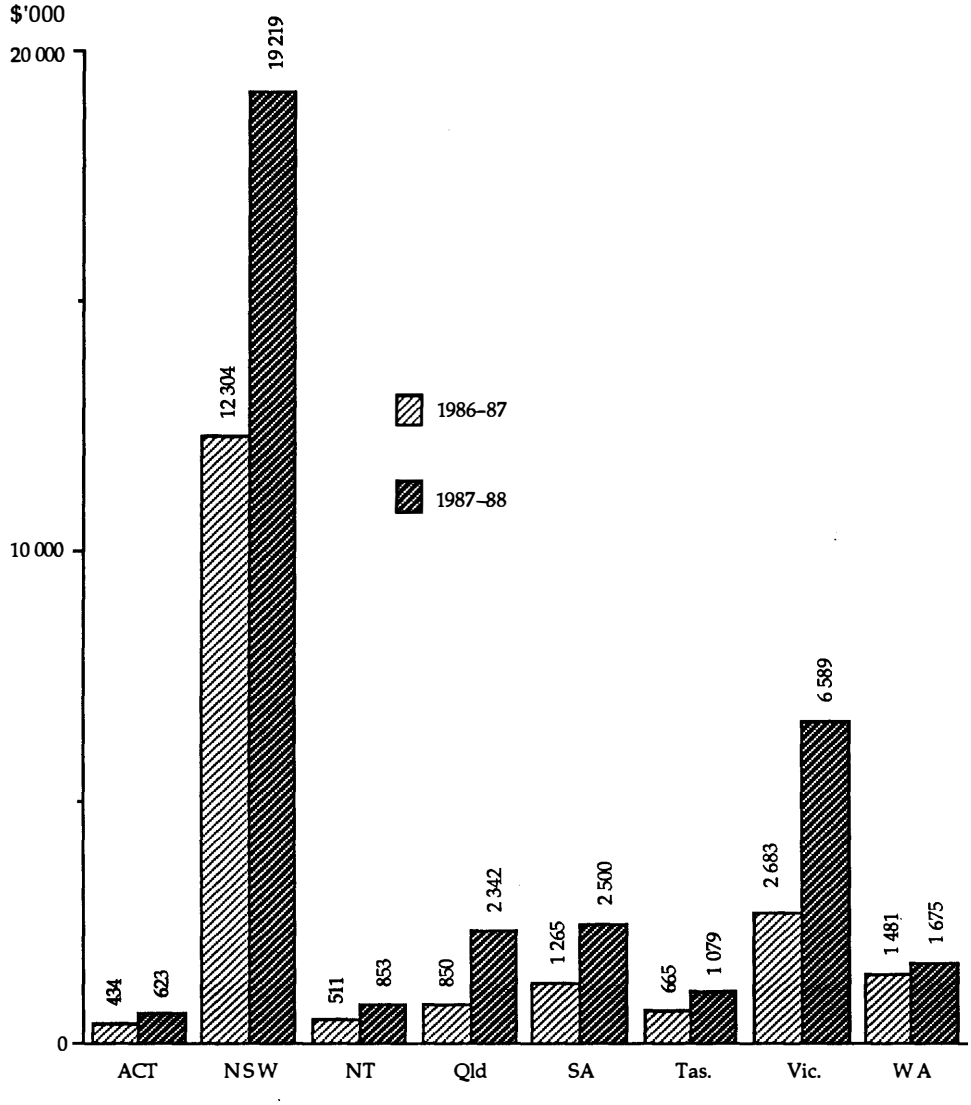
Breakup of total program related costs identified 1986–87



Source: Touche Ross 1988 a

Figure 4:

Actual and budgeted HIV-dedicated expenditure by State health authorities 1986–87 and 1987–88



Source: Touche Ross 1988 a

Disability through illness represents a loss to sick individuals and their dependents, and also to society through forgone productivity if the jobs of people incapacitated cannot be filled by people who are unemployed. Calculation of morbidity and mortality costs vary considerably depending on assumptions about expected levels of income and the rate of discount to be used. Duckett [1987] calculated an individual mortality cost of around $800 000 per person, while an estimate of around $450 000 was used for comparable age groups by Steadman and Bryan [1988] for road accident victims.

These figures would suggest a range of between $120m and $240m in 1988 for indirect mortality costs. The loss in productivity arising from the removal from the workforce of people caring for those incapacitated by HIV should be added, and productivity loss through those incapacitated by illness. With these additions, indirect costs in 1988 could be in the range $170m to $340m.

1.5.3 Costing programs of intervention

Estimates of disease costs using the prevalence model provide an indication of resources being used and possible future calls on resources. They can place HIV in the context of other diseases in terms of financial impact and focus attention on where interventions are needed. However, other costing methodologies are required to evaluate the relative merits and effectiveness of different programs and strategies.

Such methodologies could compare the relative cost efficiency or effectiveness of particular measures, or measure costs against benefits. A planning balance sheet could show the relative effects of particular strategies on different groups or sectors, for example, comparing public costs and benefits and private costs and benefits.

Program costs are straightforward to estimate. However, in practice, it will be difficult to estimate the marginal benefits of particular programs. The net benefit of the prevention of a single case of infection is the lifetime cost of care and treatment and loss of productivity while ill, and mortality cost after death. Models of costing are needed which estimate a net present value equivalent of such future costs. These estimates are complicated by the long lag between infection and illness, and therefore between implementation of a program and the realisation of its benefits, the varying rates of progression from infection to illness and the difficulty in quantifying the benefit of saving human lives.

The lack of reliable data and the uncertain nature of many of the parameters mean that such analysis is unlikely to provide a reliable and complete basis for policy decision making. However, approximate calculations can reveal the extent to which expenditure on effective preventive measures will prevent the substantial drain on resources resulting from HIV illness.

Table 7 shows an illustrative calculation based on a hypothetical case of infection involving HIV-related illness requiring treatment four years after initial infection and the development of AIDS seven years after infection. Assuming forgone annual income of $28 000 over 25 years after death and various rates of discount, the net cost of a single case of infection is around $400 000 to $600 000. This contrasts with the low costs of preventive programs such as needle and syringe exchanges and education programs for intravenous drug users, which have been proven to be effective in holding down rates of infection.

Table 7:

Net cost of a single case of HIV infection, illustrative calculation

($ '000)

Year after infection	Direct Cost	Indirect Cost		Total
		Morbidity	Mortality	
1	0	0	0	0
2	0	0	0	0
3	0	0	0	0
4	5	10	0	15
5	10	15	0	25
6	15	25	0	40
7	30	28	0	50
8	35	28	0	63
after death				
9 to 33	0	0	28	28

Total lifetime cost, expressed as value at time of infection

Rate of discount		
	3 per cent	$550 000
	4 per cent	$475 000
	5 per cent	$413 000

1.5.4 Human resource requirements

There has been no systematic study of the actual and projected human resource requirements of the epidemic.

General medical practice including STD clinics will be the main service through which HIV infection and HIV-related illnesses are first diagnosed.

Medical practitioners will require access to current knowledge, in-service and specialist courses and clinical experience in order to be able to respond.

The demand for other health care personnel, including specialists, nurses, counsellors and social workers, will expand for both hospital and community based HIV-related health services as the case load of HIV-related illnesses increases and as HIV infection becomes more akin to a chronic but manageable condition through improvement in treatment.

The expansion of care, support and treatment programs through home care services and day care centres will necessitate a review of recruitment and training procedures.

Community based programs

Community AIDS organisations have taken the lead in the provision of appropriate education and prevention programs for their membership, and in the provision of care and support services for HIV-infected people.

Community based care and support services are provided by community AIDS organisations in each State and Territory. They offer emotional and practical support for HIV-infected people, their partners and families through networks of volunteers. In June 1988 about 260 infected people were being cared for by approximately 420 trained volunteer carers, with another 220 trained volunteers available for care.

As these organisations have become more adept at providing services, they have, in general, moved towards closer relationships with community nursing services.

Almost all community AIDS organisations have full time education officers responsible for a wide range of initiatives and projects. The work of all organisations is carried out with minimal staffing and with severe budget restraints.

The Touche Ross study [1988b] found that there are insufficient personnel to service the requirements of families of people infected with HIV, their friends and other affected individuals or groups. Areas outside the inner cities, particularly country areas, lack sufficient trained personnel. Many of these areas are serviced by people with some related training but without the necessary depth of HIV-related skills or knowledge.

It is clear that volunteer based organisations provide care and assistance at considerably lower cost than normal care services, and that they can reduce significantly the number of days that a patient needs to spend in hospital.

There will be an increasing burden on community organisations as the numbers of those needing care increase. There is an urgent need for extra resources to recruit, train and retain sufficient numbers of volunteers to meet the future demand for services. Detailed costing of the provision of

services by community organisations is needed to identify and to plan the resources needed to meet future demand and to establish an appropriate balance of sources of funding. The potential savings to the community would appear to far outweigh the level of government funding to such organisations.

A national response

2.1 The need for an agreed national response to the epidemic

Public health and other authorities in all States have been faced with the visible end product of HIV infection: an increasing number of reported AIDS cases and deaths. Responses so far have mainly been localised.

Without national consensus on the most effective measures to minimise transmission, the spread of the virus will be difficult to contain. Effective education and community based programs in one State could be jeopardised by ineffective responses in other States. If treatment opportunities vary between States, people will gravitate to hospitals or States offering their preferred treatment rather than remaining near the support of friends and families. Infected individuals, fearing the law in one State, may move to a State where they are unknown or where the law is used differently. The uneven availability of counselling services or support groups could cause further movement of infected people.

At this early stage there is time to reach agreement throughout Australia on how best to assess the magnitude of the epidemic, to develop appropriate policies against further transmission, and to make provision for those infected.

Much of the infrastructure required to implement a National AIDS Strategy is in place. State, Territory and the Commonwealth governments have established AIDS bureaus responsible for policy development. Many States are developing a State strategy. The Commonwealth Minister for Community Services and Health has appointed the Australian National Council on AIDS (ANCA) to advise him. Other governments have similar advisory bodies.

The Commonwealth Minister for Community Services and Health has convened a Parliamentary Liaison Group with members drawn from all political parties and independent parliamentarians to ensure that all politicians are informed and to provide a forum for policy discussion. A number of State governments have established bipartisan bodies to assist in policy development and consultation.

Each State and Territory has an AIDS Council which represents, or is in touch with, a wide range of community groups involved in HIV education, prevention and care programs. These AIDS Councils have formed a national organisation, the Australian Federation of AIDS Organisations.

Intergovernment liaison and coordination is achieved through the Intergovernmental Committee on AIDS, which has representatives from the finance and policy sections of all State, Territory and Commonwealth health departments.

Special units have been established for research into AIDS virology, and AIDS epidemiology and clinical research under the aegis of the National Health and Medical Research Council (NHMRC). These two units are funded by the Commonwealth, advised by the Australian National Council on AIDS on the allocation of funds for HIV research. However, there is as yet no unit responsible for social and educational research on HIV infection.

The NHMRC Special Unit in AIDS Epidemiology and Clinical Research, at the University of New South Wales, Sydney, has responsibility for collecting and publishing epidemiological data, serving as a focus for epidemiological and clinical research, and organising clinical trials of antiviral drugs.

The NHMRC Special Unit for AIDS Virology has its headquarters at Fairfield Hospital, Melbourne, and operates through a network of collaborating laboratories located throughout the country, including Melbourne, Perth, Adelaide, Sydney and Brisbane. It undertakes and coordinates research into the virology of HIV, screens new drugs with potential antiviral activity and participates with the Sydney Unit in clinical trials of antiviral drugs.

Commonwealth and State government regulations have restricted testing for HIV to nominated Commonwealth and State diagnostic laboratories and the National HIV Reference Laboratory (NRL). The NRL is based in the Fairfield Hospital, Melbourne and is responsible for evaluating new diagnostic tests; coordinating and evaluating quality control for HIV testing throughout Australia, and confirmation of equivocal results submitted by the State Reference Laboratories. Nominated State diagnostic laboratories perform routine ELISA tests for HIV, and positive sera are forwarded to designated State reference laboratories for confirmatory tests.

The infrastructure is in place; it may need to be strengthened within the context of developing a National AIDS Strategy.

An agreed national response would not necessitate uniform approaches. This may occur or, alternatively, agreement could be reached on an appropriate diversity of policy initiatives, all deemed capable of achieving the objectives of the Strategy. It is important that agreement be reached on the need to move towards accord at all levels of government and between government and the community on a National AIDS Strategy.

2.2 Objectives of a National AIDS Strategy

Three objectives for a National AIDS Strategy are proposed:

1 To minimise transmission of the Human Immunodeficiency Virus (HIV).

2 To support, care for and to treat people infected with HIV.

3 To educate and to prevent the infection of people who care for infected individuals.

Historically, the first two objectives have been either explicitly or tacitly accepted. Identifying the need to educate and to prevent the infection of people who care for infected individuals as a separate objective of the National AIDS Strategy recognises the carers and the value of the work that they perform.

Counsellors and social workers, families, partners and friends, community organisations, and existing home care services, especially the community nurses, have responded to the needs of HIV-infected people. Volunteers and staff in respite care centres, hospice staff, bereavement counsellors, specialists, doctors, nursing staff, dieticians and physiotherapists are all involved in helping those affected.

The choice to care for an infected individual should not put anyone at unnecessary risk of HIV infection; nor should it cause emotional, psychological or physical harm to the carer.

A number of other aims have been proposed as objectives for the Strategy. These include encouraging and supporting HIV related research and evaluation, establishing effective government and community management and communication structures and preventing discrimination based on people's actual or perceived infection status. All these are discussed as components of a National AIDS Strategy.

2.3 Guiding principles proposed for the development of a National AIDS Strategy

Many of the issues on which policies need to be adopted in the formulation of a National AIDS Strategy are complex: moral, legal and social factors will need to be taken into account. It is important that agreement be reached on a set of principles to guide policy formulation.

Under some circumstances there may be exceptions to particular principles, or some may need to be overridden. However, any departure from the principles should be carefully justified.

The principles set out here are not exhaustive. However, reaching consensus throughout Australia will ensure a common approach to developing a national response to the virus.

Policies should be formulated on the basis that transmission of the virus is preventable

Technological developments have enabled the securing of the supply of blood, blood products and human tissue. The ways the virus can spread through the community are known and are limited to unprotected sexual contact with an infected person, the sharing of needles or other drug using equipment with an infected person, accidental exposure to infected blood and from mother to child perinatally. Knowledge of the modes of transmission enables further spread to be minimised through appropriate changes in behaviour.

Extensive understanding of the nature of the epidemic is essential to the development of sound policies

An extended program of public information and education will enable the community to make suitable responses and to judge the appropriateness of policies initiated by governments. The community, and especially its leaders, should be informed about the most effective, efficient and least intrusive policies to stem the spread of the virus as well as provide for those infected.

Each person must accept personal responsibility for preventing himself or herself becoming infected through sexual intercourse or through sharing of needles and for preventing further transmission of the virus

Acceptance of this principle will determine the appropriate function of both education and the law. Universal acceptance of the principle as a determinant of behaviour would mean that each member of the community could live without fear of infection by these means. Individuals who are infected can, by adopting this principle, prevent transmission to others. This principle does not address transmission by other means such as perinatal transmission or transmission through the blood and blood product supply.

The Australian community has the right to access to appropriate protection against infection

Access to information, education and the means of prevention should be widely available. Efforts should be made to allay fears and clear up misconceptions, and to address concerns about policy initiatives.

Educational measures and prevention programs can bring about behavioural changes to minimise transmission

If voluntary behaviour change were not possible, the only measures available to minimise transmission would be enforced quarantining or enforced behaviour change. However, research in Australia has shown that educational approaches, including counselling and self-help groups, peer group support, and prevention programs such as condom advocacy and distribution have brought about sustained changes in sexual behaviour in high risk groups. There is also some evidence that people at risk through drug use have changed their behaviour. Further, there are many values in our society relating to marriage and personal and sexual responsibility which complement means of minimising transmission. These factors justify a continuing acceptance of the primary role of education and prevention programs in the National AIDS Strategy.

The law can complement and assist education and other public health measures

The law has a positive role in supporting and reinforcing education and other public health programs to minimise transmission and to assist those infected with HIV. The epidemic has raised a number of important legal issues: the need to balance the rights of individuals with those of the community, the role of the law in assisting behaviour change, and the effect

on public health measures of legal sanctions. In the resolution of these issues, care should be taken that the use of the law is neither detrimental to achieving public health objectives, nor discriminatory.

To be effective, policies will require the continuing cooperation of those at risk of infection

Almost all modes of transmission, including perinatal transmission, occur in the course of private, often intimate, behaviour. Although the nature and the consequences of infection may seem to indicate interventionist action, it should be accepted that preventing transmission involves changes in personal behaviour which can be brought about voluntarily. Without cooperation and trust between those at risk and the public officials concerned, people at risk may place themselves beyond the reach of policies designed to assist them, and to stem the spread of infection.

People infected with HIV retain the right to participate in the community

HIV-infected people do not pose a threat to others through normal everyday contact and, like all who contract an illness, should remain within the community without unjustified discrimination in any area of life. They need equal access to employment, and to education and training which enables them to find employment and to stay employed for as long as possible. Discrimination based on a person's infection status or perceived infection status needs to be addressed if their rights are not to be impaired.

Confidentiality regarding a person's HIV infection status should be maintained

Infected individuals need to retain control over disclosure of their HIV infection status to ensure that adverse consequences are minimised. Specific consent should be given by an individual before any such disclosure takes place, except where it is required by statute for public health purposes. Where such disclosure is required, notification should be in an anonymous or coded fashion. Any person informed of another's infection status should have specific consent for further dissemination of the information. Procedures for handling information of this nature, in health institutions, government departments or agencies or elsewhere, should be reviewed for adequacy in their formulation and implementation. Breaches of this principle will lead to a loss of trust and cooperation of people at risk of infection.

Specific informed consent should be obtained before any test is performed

For all medical interventions, it is widely accepted that consent means an informed, voluntary and uncoerced decision. This principle may be overridden in certain specific circumstances. The possibility of social, financial and personal consequences from having had an HIV test, as well as from a positive test result, requires counselling about the significance of the test itself. Specific consent for carrying out the test should be sought. Consent to general and unspecified tests cannot constitute specific consent to the testing of a person's HIV infection status.

People infected with HIV have the same rights to comprehensive and appropriate health care, income support and community services as other members of the community

Wherever possible and appropriate, existing services should respond to the needs of infected people. Because of the fear and stigma surrounding HIV infection, there is a need to work with staff and management of existing service organisations to address their concerns and to meet the identified needs of HIV-infected people. However, in some cases where the required services do not exist or because of a unique feature of HIV infection, HIV-specific services may need to be developed. Services will be needed by community based carers as well as by infected people themselves.

Carers for HIV-infected people have a right to protective and supportive working environments and a responsibility to minimise occupational transmission

Occupational transmission in health care settings has been reported in a small number of cases. Such transmission is usually associated with a lack of adequate procedures to prevent accidents or to ensure infection control in hospital or in community situations, or with a failure to adhere to prescribed procedures. The necessary procedures are simple and can reduce significantly the risk of HIV infection. Nevertheless, a risk exists and the concerns of health care workers and other carers need an appropriate response. The provision of care to HIV-infected people may cause severe stress so supportive measures should be instituted to protect the health and welfare of the carers.

Objective 1:

To minimise transmission of the Human Immunodeficiency Virus

3.1 Minimising the spread of HIV

It is critically important to prevent the spread of HIV in Australia. The necessary changes to individual behaviour, social policy, community opinion and legislation will require a substantial and coordinated national prevention program.

Australian governments and most sectors of the Australian community have agreed that a significant and increasing commitment of resources to prevention is in the national interest and that the cost of HIV infection, in terms of human life and the financial burden to the community, must be contained.

Many Australians view HIV infection as a serious health threat: seventy-four per cent of respondents in a recent nationwide survey thought that AIDS would eventually become an epidemic for the Australian public at large [NACAIDS 1988]. Preventing the spread of HIV will not be cheap. But it is apparent that the cost of prevention will represent a very small fraction of the potential cost, economic and social, direct and indirect, of an uncontrolled epidemic.

Governments cannot prevent the transmission of HIV. Only individuals can do so by changing the sexual or drug using behaviours, or particular work practices which put them at risk, and by taking personal responsibility for avoiding infection.

However, governments are responsible for the protection of the community as a whole and the maintenance of public health. They have already secured the safety of the blood and tissue supplies from HIV and have developed and implemented infection control procedures for occupational risk situations. In the further prevention of HIV, they are responsible for ensuring that all members of the public have the necessary information to protect themselves and to put into practice the necessary behaviour changes.

Without coordinated preventive activity, the virus will spread unchecked through unsafe drug use and sexual behaviour, and from women to their children. The experience of many other countries where preventive activity has been slow or spasmodic gives ample evidence of this possibility.

Education and prevention programs are our best weapons against HIV. Prevention programs include ensuring that all sexually active people have access to condoms, that sterile drug use equipment is widely available and that the blood, blood product and human tissue supply is uncontaminated. Mass education programs can assist individuals to change and face-to-face education and counselling can help them to sustain behaviour change, but other environmental factors outside their control can stand in the way of prevention. For example, intravenous drug users who do not stop using

drugs can only avoid sharing equipment if there is an adequate supply of sterile equipment, readily accessible without fear of legal penalty, or if there are no reusable syringes in the country. Either of these options can only be achieved by legislative action.

People who are considered a high priority for education, for example male prostitutes, are difficult to reach with education if their activities can bring them into conflict with the law. Legislative change could make access to this group easier.

Careful consideration must be given to changing the law in order to minimise transmission of HIV and to remove any impediments to public health objectives.

Prevention measures, along with the removal of legislative and social barriers to the required behavioural change, can complement and reinforce education programs.

3.1.1 Sexual transmission

HIV is sexually transmitted. Strategies for preventing further sexual transmission need to be based on this fact.

The strategies for avoiding or minimising the risk of sexual transmission of HIV are clear:

abstinence from sexual activity;

a monogamous relationship with someone who is known to be uninfected and in whom implicit trust can be placed to remain uninfected;

refraining from anal sex, or using a rubber condom every time;

sexual intercourse only with a partner or partners who are uninfected and who do not engage in risk behaviour; and

using a rubber condom every time in sexual intercourse with people where HIV infection status is doubtful or unknown.

Legislation has been used throughout the ages in attempts to control human sexual behaviour but has generally failed to do so. There is increasing debate about the desirability and practicalities of legislating against adult sexual behaviour.

In some jurisdictions in Australia, prostitutes avoid contact with authorities because of the legal sanctions against activities associated with prostitution (Section 3.5.8). This has made reaching them and their clients with

education about safer sex and prevention of HIV transmission more difficult.

Homosexual activity between males has been illegal in most jurisdictions and is still illegal in Queensland, Tasmania and Western Australia, although only randomly and rarely enforced. The activity has often remained hidden because of the fear of legal and social penalty. Denial of sexual orientation, privately or publicly, is a significant barrier to education about the need for safer sex.

It is most likely, given the last five years' experience with HIV prevention, that education, not the use of the law, will be more successful in achieving the desired sexual behaviour changes to stop the spread of the virus.

Educational programs need to be developed from existing knowledge about human sexual behaviour. A variety of research provides evidence that from puberty many adolescents experiment sexually; that at least one married man in 25 has occasional male to male sex [Ross 1988]; that many heterosexual and homosexual couples have sexual encounters outside their regular relationship; that young people may have several sexual relationships before settling down with one partner; and that, with one of the highest divorce rates in the western world, many heterosexual Australian adults may have several monogamous relationships, one after the other.

This means that education will need to promote safer sex as a normal aspect of any relationship which involves sexual activity. Education campaigns will need continually to reinforce the message that sexual transmission of HIV should concern homosexual, bisexual and heterosexual individuals.

If campaigns confront denial and make HIV personally relevant, they can generate an understanding among all people who are not in life-long and reliably monogamous relationships that they could become infected through their sexual behaviour.

Educational strategies for particular sexually active populations are discussed in more detail in Section 3.5.

3.1.2 Transmission through the sharing of needles and syringes

The strategies for avoiding HIV infection through the sharing of needles and syringes are known:

abstinence from all drug use;

drug use without injecting;

intravenous drug use without sharing equipment; and

intravenous drug use with equipment which is cleaned after each individual has used it.

In all jurisdictions in Australia, the law prohibits the possession, use or supply of most of the drugs used by intravenous drug users including heroin, cocaine, amphetamines and drugs like XTC. The law has also prohibited the possession, use or sale of injecting equipment, although this has now changed in most States and Territories. Provisions relating to injecting equipment have been or are being reviewed in all jurisdictions except Tasmania so that sterile injecting equipment may be made readily available.

To prevent transmission of HIV, the behaviour to be changed is simply the sharing of any equipment contaminated with HIV. Education alone will not be able to achieve this and changes to the law in every jurisdiction may be required. Other changes in the law may assist health and education authorities to locate intravenous drug users and to offer both education and a range of options for substituting either the drug or method of administration.

3.1.3 Perinatal transmission

Transmission of HIV from mother to baby may be especially difficult to prevent.

There are several strategies for preventing or minimising perinatal transmission of HIV:

prevention of HIV infection in women and girls of childbearing age;

voluntary HIV testing before marriage or before pregnancy;

contraception for women who are infected; and

abortion for infected women who become pregnant.

Education of women of childbearing age and younger is a complex, high priority task. Educational programs should be delivered through the wide range of health and education services catering for women and girls. Girls and women may be motivated to adopt and insist on safer sexual practices with their partners to ensure that their children will be safe from HIV infection.

For women who are already infected, the educational issues are especially sensitive. Any woman who is infected will need access to additional counselling about pregnancy, abortion, infant death and the parenting of an infected child.

The provision of continuing counselling services to infected women or couples may be necessary, whether or not they choose to have children and whether or not those children are infected with HIV.

Education and counselling of infected women is the most sensitive and appropriate measure to minimise perinatal transmission. Legislation to prevent them from bearing children would present moral, political and administrative problems and is unlikely to be enforceable.

3.2 The role of education in minimising transmission

3.2.1 Education for prevention

Education is the principal means of preventing the spread of the virus. As part of the overall prevention strategy, education about HIV has three objectives: to ensure all Australians realise the seriousness of HIV infection and understand how HIV is transmitted; to enable individuals to assess their own level of risk and protect themselves from infection by changing sexual or drug using behaviour; and to reduce unnecessary fears about HIV or people infected with HIV in the community.

Some progress has been made towards each of these objectives but the spread of HIV has not stopped. The range of behaviours to be addressed by education programs to minimise all modes of transmission are personal, private and often deeply entrenched. The acceptance of the need for prevention and the abandonment of some risk behaviours may represent very real and deeply felt losses to many in the community.

Widespread behaviour change is unlikely to occur in an antagonistic or apathetic environment so continuing to try to change public opinion about the realities of HIV will be crucial to sustained behaviour change. There is still some opposition to explicit educational messages and radical prevention programs.

Factors favouring preventive education

There is widespread awareness of HIV and the modes of transmission, and acceptance by many that further education about HIV and HIV-related illnesses is necessary. Some of those most at risk of HIV infection have already adopted safer behaviour.

However, this is only the beginning. By themselves these factors cannot achieve the necessary level of behaviour change.

Barriers to preventive education

Experience in the last five years has identified a number of significant barriers to preventive education.

Individual attitudinal barriers, primarily denial. While knowledge of HIV transmission is high, acceptance that one could be personally at risk is not widespread outside the homosexual community. Denial of risk may be based in some of the myths which still surround HIV, in the need to maintain belief and trust in personal relationships in spite of the possibility of

infidelity, or in the romantic attitudes to love which often surround sexual activities.

Status barriers. These consist of communication difficulties relating to age, literacy, language or culture, and physical or intellectual disabilities.

Behavioural barriers. Other activities may impede the acceptance, adoption or sustained practice of safer behaviour. These may include alcohol or other drug use in pre-sexual contexts, dependence on intravenous drugs and lack of assertiveness in sexual relationships.

Environmental barriers. Some legal and social factors may militate against the practice of safer behaviour. These include social acceptability of condom use, peer pressures to conform to certain styles of unsafe sexual behaviour, high rates of separation and divorce, a person's financial situation, and the availability of sterile equipment for intravenous drug use.

Public education now needs to move beyond the process of improving knowledge of HIV transmission and into a process which motivates and supports people to put knowledge into practice.

3.2.2 A national education strategy

All Australians should be educated about HIV, about their personal level of risk and personal prevention strategies. Progress can be made towards achieving this objective with the development and resourcing of a comprehensive and consistent national education program.

Objectives of a national education strategy

There are three specific objectives for a national education strategy:

1 To increase community acceptance of the seriousness of the HIV epidemic and of the necessity for national preventive action.

2 To enable individuals to assess their personal level of risk for HIV infection and accept personal responsibility to abandon behaviour which may permit the transmission of the virus.

3 To reduce unfounded fears of infection and prejudice towards HIV-infected individuals, and to increase support for infected people.

Educational research indicates that a successful strategy to meet these objectives would be based on current and developing knowledge of the following factors:

the risk behaviours which must change and the cause or circumstances of risk taking;

each distinct target group for education and the prevalence of risk behaviour in that group;

the barriers to behaviour change, personal, social, legal, political in each group;

the incentives for behaviour change in each group;

the nature of appropriate messages to promote change in each group;

the medium or combination of media and other channels of communication available for education, and credible to the target group;

the placement of messages and programs to maximise access to the target group;

the methods for achieving continuity of messages and programs; and

the mechanisms for monitoring, evaluating and improving the effectiveness of the strategy.

Choice of target groups for education

Ultimately, education about HIV needs to reach every Australian. However, not all Australians are now at the same level of risk of infection. Nor is it likely that sufficient human or financial resources would be immediately available for the task of educating everyone in the country.

An education strategy may need to address a number of specific and different groups. Highest priority should continue to be given to those currently most at risk of becoming infected. These are homosexual or bisexual men, the female partners of bisexual men, casual or regular intravenous drug users, Aboriginal people, people in prisons and men, women and adolescents who work as prostitutes and their clients. High priority should also be given to the education of those who are infected and may transmit the virus to others. These include people infected through contaminated blood or blood products and infected female intravenous drug users of childbearing age.

However, a strategy cannot be limited to these groups since the transmission of HIV to others outside these groups has begun. These include young people, because of the probability of sexual or drug taking experimentation during adolescence and early adulthood; health and emergency workers who may not yet be adopting strict infection control and accident prevention procedures; people who travel to other parts of the world where HIV infection is widespread; and the sexual partners of people at highest risk.

Subsidiary programs to maintain and gradually increase general public understanding of HIV would continue to reach those at lower risk.

Some sectors of the community regard as the only acceptable messages those which promote prevention through abstinence from sexual activity and from intravenous drug use, or through life-long monogamous relationships. To others, such views are unrealistic and only the promotion of sexual or drug using practices which minimise the risk of exchanging body fluids is seen as a valid response. Acceptance of diversity will be fundamental to the success of the National Education Strategy.

The audience for HIV education needs to be broken down into a small number of subgroups which are as internally homogenous as possible, and at some specific risk of HIV infection. For example, programs developed for the majority of young people who do not use drugs will focus on preventing them from beginning. Programs for young people who have already experimented would be more likely to focus on stopping use, or on not sharing equipment. For young people who are dependent on intravenous drug use, the focus would be on not sharing equipment or on cleaning shared equipment, on reducing drug use and on seeking help or treatment.

Barriers and incentives to change

Research about each target group needs to be undertaken to provide data on the prevalence of the risk behaviour, the circumstances in which it occurs, the perceived benefits from continuing the behaviour and the perceived losses from abandoning it, and the group's attitudes and values.

For example, there is inadequate research about sexual activity among young people, although there is evidence that few consistently use condoms [Australia Market Research 1987]. In order to educate sexually active young people about safer sexual practices, much more will need to be known about why they do not use condoms and what the barriers are. Incentives to use condoms need to be found and emphasised in education programs.

Education for young people who are not sexually active could focus on different strategies for protection, including the choice of abstinence or of postponing first sexual experience.

For each group to be addressed, these barriers and incentives need to be known and taken into account in developing appropriate messages and programs.

The education message

The simple assertion that HIV infection is preventable has not yet been enough to achieve prevention. Future educational campaigns will need to develop from the starting point of convincing each individual that HIV infection is preventable; there is no evidence of casual transmission; each can personally minimise the risk of HIV infection; each can choose their own way of staying safe from HIV infection; and, it is essential to continue with safer behaviours.

The way in which any or all of these concepts are turned into campaigns or programs will depend on the specific target group. Educational messages need to prompt individual recognition of risks and motivate the adoption of safer behaviour. What prompts recognition and breaks denial about unsafe sex in an adolescent girl will be different from a message which achieves the same effect for an adult homosexual man. An acceptable message to an intravenous drug user may seem shocking or irrelevant to a non-drug user.

Choice of medium for access to the target audience

Education can take place in almost any context, not merely in those which are obviously educational or preventive, but also in those associated with research, crisis intervention, community action, treatment, counselling or testing. HIV education should become an integral aspect of health, welfare, education and community services.

The appropriate choice of media will be limited by the financial or human resources available, and will depend on several factors. First, it can be determined by what is known about the media habits of the target audience. Secondly, it has to be established which media, individuals or groups are considered credible by the target audience, for example, whether the message is more likely to be heeded if it is delivered by a doctor or a rock star. While much of this information is available about the general population, much less is known about these factors as they apply to the priority target groups for HIV education.

Thirdly, the choice of media is determined by other relevant education and communication variables. The words and images, the materials and programs developed will need to take many forms to accommodate the different physical, educational and social characteristics of people in each target audience.

The medium may also be determined by the existence of infrastructures which have access to the target audience. Reaching young people under the age of 16 will often be most cost effective and simple if delivered through school based programs.

The perception of HIV education as consisting of a series of infrequent television commercials needs to be replaced with the understanding that such commercials constitute only one aspect of the education strategy. The mass media represent the most visible and cost effective means of reaching large numbers of people at one time with a simple message. However, such messages cannot alone change behaviour. The most successful mass media education campaigns, for example the Drug Offensive campaigns run in Australia since 1985, are supported by other forms of more direct contact with individuals at the community level, like face to face programs in schools, community groups and workplaces, counselling and treatment services, and outreach programs.

In choosing the appropriate medium for messages aimed at specific target groups, it needs to be remembered that many of the highest priority groups for education, such as intravenous drug users and homosexual men, have proved to be far less homogeneous than at first thought. Where the risk behaviour is the only factor which these individuals have in common, the mass media may be the only way of ensuring that information reaches the majority. While media messages about the dangers of unprotected anal intercourse, or sharing equipment for intravenous drug use may seem unpalatable, and may cause some controversy, they may be necessary to achieve the educational objectives.

Choice of educational techniques

There are many different educational techniques which can be used. The choice will depend on what is known about the people in the target group, and what is known about the effectiveness of different techniques in persuading individuals to change unsafe behaviour or to maintain safer behaviour.

Peer education is proving particularly effective especially when previous experiences have led to mistrust of authorities or to limited credible sources of information. Current intravenous drug users often find former users more credible than educators who have never used drugs, and prostitutes are demonstrating a high level of response to education delivered by other prostitutes and former prostitutes. Peer support can continue after formal education programs are completed and can play a crucial role in sustaining behaviour change.

Education with small groups of people who have particular experiences in common has produced positive results, for example, in educating the sexual partners of people who are infected or groups of workers in drug treatment agencies.

One to one counselling is one of the most effective educational interventions. Although it is intensive in effort, it may well produce the best results in achieving behaviour change. Less extensive interventions on a one to one basis can be very important. For example, general practitioners could provide all patients with basic information about prevention of transmission.

Developing the short-term education strategy

It will be some time before the success or otherwise of preventive education can be assessed. The prevention effort will be aimed at slowing the spread of the virus by educating more and more people to abandon unsafe behaviour.

Although the long-term aim is still to persuade all adolescents and adults about the dangers of unsafe sex and unsafe drug use, that probably cannot be achieved within the next two to five years. During that period, the principal effort should address those who are currently at higher risk of infection,

those for whom prevention of transmission can most readily be achieved, and those whose position in our society gives them authority or influence over the behaviour of others.

A short-term education strategy could also stimulate public debate about drug substitution programs or alternative methods of using drugs. It would require commissioning research into the situations in which needle sharing occurs and the motivations for the behaviour.

For sexually active adults and adolescents, a substantial effort should be considered to change society's perceptions of masculinity and femininity; the public image of condoms and people who use them; and attitudes about responsibility for safer sex and contraception. Both men and women need to be taught the skills of negotiation and assertiveness.

There are special communication needs for some groups which need to be given high priority. These groups include Aboriginal and Islander people and those for whom English is a second language.

Another important factor in behaviour change is the provision of credible role models. To address all parts of society, the good will of leaders, politicians, rock stars, church leaders, sportsmen and women, and community representatives should be sought to guide their supporters or constituents in preventing further HIV transmission.

Community leaders generally can become advocates for prevention or they can become opponents of the educational messages which will be promoted. It is only with their support that the strategies can succeed.

Any decisions about priorities for education will need to be reflected in the allocation of Commonwealth, State and Territory resources: in committing human and financial resources to priority areas; in the consultative and cooperative mechanisms established to develop and implement education programs; and in funding specific community based projects.

Possible policy components

- Develop programs:
  - for those who are currently thought to be at higher risk of infection with HIV;
  - for those who are considered most likely to be at risk in the near future;
  - for all Australians, regardless of risk status;
  - which differ in resource input according to individual or group risk status;
  - which differ in resource input according to the program's potential to minimise transmission.
- Develop and deliver such programs:
  - at Commonwealth, or State and Territory levels;
  - at community level;

  - at all levels;
  - through a mix of levels depending on effectiveness and outreach.
- Establish monitoring and evaluation procedures to assess effectiveness and outreach.

3.3 Other public health measures

3.3.1 Testing to minimise transmission of HIV

A number of measures to minimise HIV transmission have been proposed including education and prevention programs for people known to be infected, counselling to prevent infection or further transmission, compulsory treatment, legal sanctions against knowingly transmitting the virus and quarantining of infected people. Implementing these measures depends upon knowledge of a person's infection status. The most reliable method of determining a person's HIV status is to test for the presence of antibodies to the virus or of the virus itself.

The use of testing to establish a person's HIV infection status raises serious considerations relating to consent to testing, confidentiality and counselling which apply to testing in all circumstances.

Technical aspects

Testing for HIV infection is most commonly carried out on blood specimens, usually to detect antibodies. Some tests detect the virus itself or parts of it, and tests can be performed, but are not routinely done so, on semen, vaginal and other secretions, and on organs and tissues.

No test procedures are likely to be perfect. Problems include human error in the labelling of specimens, conduct of the tests and interpretation of the results, and the small but unavoidable levels of false negative and false positive results.

The most commonly used HIV tests detect minute concentrations of antibodies in the blood of infected people. These antibodies take a variable period to be produced and reach detectable levels some time after initial infection with the virus. Thus some tests on infected people carried out in this early period are negative. A small proportion of tests on specimens that contain HIV antibodies may also be falsely negative, while another small proportion of tests carried out on specimens from people who are not infected may be falsely positive. Most of the latter are detected by the routine performance of confirmatory tests.

False negative tests are much more likely to go undetected because negative tests are rarely rechecked unless there is some special reason to suspect HIV infection. While the prevalence of HIV infection in the population group being tested remains low, there will be very few false negative tests. If the prevalence of HIV infection increases false negative tests may become of greater concern to public health, and eventually a problem in screening blood for transfusion.

Confidentiality

Information concerning HIV infection is acutely sensitive. Releasing such information can have devastating and irreversible consequences for the individuals concerned. Stringent confidentiality procedures should be established and enforced in any system for testing people for HIV, and everybody concerned should be educated to a high level of commitment to preserving confidentiality.

Legal options for the protection of confidential information are discussed in some detail in Section 4.5.

Without credible guarantees of confidentiality, those at risk of infection may be reluctant to be tested. The request for testing is often the first point of contact for HIV-infected individuals with the health care and public health systems. Early contact enables counselling, educational and support measures to be set up, which lead both to the care of the infected person and to the prevention of HIV infection in others.

Confidentiality does not relate merely to positive test results. The fact that a person has been tested, counselled, or even has attended an HIV facility, can have unpleasant consequences for individuals. Knowledge of a person's sexual orientation or practices, their use of drugs or of other behaviour, may also have negative consequences.

There can not be a system that guarantees absolute confidentiality. Any system depends on the people who operate it, and human error or weakness may lead to its breaking down. People considering HIV testing need to be made aware of this possibility and may choose to give false names.

The most common source of disclosure of HIV status will continue to be infected people themselves who often experience an overwhelming desire to share the burden. They should be counselled against unnecessary disclosure, but also counselled on the need for disclosure in any circumstance in which another person could be put at risk, including those whose occupations may endanger them, for example surgeons, dentists or people drawing blood. Disclosure to sexual and needle sharing partners should be advised since a risk of transmission remains even when correct procedures are followed.

The need for specific consent and for confidentiality are not unique to HIV infection. The standards set could benefit people with other debilitating and fatal illnesses.

Consent and counselling

Issues relating to consent and counselling have been raised in regard to other infections and other tests. They have been decided in most cases by the medical profession and public health authorities without much public discussion. For instance, pregnant women have been screened for syphilis

for over 60 years without giving specific consent, and usually without knowing about it unless the test proved positive. Many routine examinations have been and still are carried out on patients admitted to hospital without any counselling or consent given by the patients.

The common law position relating to consent in Australia, based on cases decided in South Australia and New South Wales, is that a patient has the right to be informed of the implications and potential risks of any proposed medical procedure and of the alternatives, and a right to participate in making a decision which affects them [Law Reform Commission of Victoria 1987].

In some circumstances, the requirement for informed consent may not apply, for example in emergency situations, or if testing is required by law, for example in the legislation of Queensland, Tasmania and the Northern Territory for the compulsory HIV screening of prisoners.

While it is possible that exceptional circumstances may arise in which the public good or some other consideration may require individuals to be tested without their consent, each such case should be determined individually, as an exception to an established rule.

The New South Wales Privacy Committee has published guidelines for HIV antibody testing which include the policy that all testing should be performed with prior informed consent, unless otherwise provided by law [New South Wales Privacy Committee 1986].

Testing without specific consent amounts, in the absence of any overriding justification or necessity, to an infringement of personal liberty, and may constitute an assault on the person tested.

The legal requirements for the nature and amount of information that must be provided to people to obtain their informed consent are not clear [Law Reform Commission of Victoria 1987]. Genuinely free and informed consent cannot be given unless the individual fully understands the procedure and the possible results of having taken the test. Pre-test counselling enables both the individual and the counsellor to form an opinion of the individual's likely reaction to the possible outcomes of the test, and therefore of the balance of benefit and detriment to the individual. Counselling is not merely a formal prelude to testing, but part of the process of determining whether an individual should be tested or not.

Post-test counselling is also important. The implications and consequences of the result of the test in terms of the individual's and the community's interests should be carefully explained, and the individual's psychological and emotional reactions to the result monitored and responded to by an experienced counsellor.

Testing as a public health measure

The testing of individuals and human products for HIV infection is a component of public health measures to minimise transmission of the virus.

Under certain circumstances testing may be necessary to enable special precautions to be taken to reduce the risk of HIV transmission from infected people to others.

The testing of blood for transfusion and blood products for treatment purposes, and blood testing when donating semen for artificial insemination or organs and tissues for transplantation has been universally accepted as being necessary to prevent transmission of HIV to the recipients.

Testing to identify HIV-infected people may become a desirable public health measure if safe treatment which reduces infectivity becomes available.

Testing for HIV infection may encourage people to change their behaviour to reduce the risk to themselves of becoming infected with HIV or the risk of transmitting the infection to others.

Proposals have been put forward for the compulsory testing of the entire population or of various groups perceived to be at risk of infection. A crucial issue in a number of options that have been proposed for the use of the HIV test is whether the public health benefits of testing can warrant overriding the principle of informed consent.

Testing to influence behaviour change

Since compulsory testing could prejudice gaining the cooperation of those involved, testing to influence behaviour change needs to be done with consent.

There is evidence that with counselling, people found to be antibody positive are more likely to change their behaviour. This is particularly true if the individual does not already identify himself or herself as being at risk of infection. On these grounds, there may be justification for actively encouraging testing, but only with appropriate counselling.

Some people will modify their behaviour without seeking to know their infection status, choosing this course from knowledge of the profoundly traumatic psychological and emotional impact that a positive test result can induce.

Testing the entire population

From time to time it is suggested that the entire population should be tested for HIV infection; that once it is known who is infected, it is possible to treat them, to isolate them, or in some way to prevent them from infecting others, thus curtailing the spread of the virus.

Such arguments are usually based on previous uses of widespread compulsory testing, particularly for tuberculosis. However, since HIV infection is not a curable condition, only palliative and remission treatment could be offered to those found to be infected, and since they could be numbered in the tens of thousands, it would not be possible to isolate them except by the harshest of methods. In the absence of effective treatment, the justification for quarantine would apply for the lifetime of the infected person.

Testing would be expensive. The annual cost of collection of specimens, testing and statistical analysis, based on two tests of the entire population in a single year, is estimated at $916m. This does not include capital costs associated with the establishment of new testing laboratories or HIV clinics, or purchase costs of new equipment. Nor does it include the cost of testing all incoming travellers, ensuring no one escapes testing, or costs for follow-up of people found to be infected, such as quarantine or post-test counselling.

The limitations of the currently available HIV testing technology would also work against the supposed benefits of such a campaign. In populations where the level of infection is low, and large numbers of people are to be tested, the rate of false positive and false negative results associated with current HIV testing procedures could be unacceptably high.

There is a need to demonstrate the benefit to be derived from mass compulsory testing which would outweigh the social and financial cost. While it can be shown that cooperation between public health authorities and the communities at risk continues to be effective in containing the spread of infection, it can be argued that coercive methods are not necessary.

Testing of people believed to be at higher risk

A majority of those at higher risk are believed to have already voluntarily sought testing. Test sites and hours of service may need to be expanded, particularly into suburban and rural areas, since it is critical that all those at higher risk of infection have easy access to testing facilities.

Suggestions to test all homosexual men or all drug users compulsorily raise immediate questions of definition, enforcement and subsequent action. There is no way of identifying all the men who have sex with other men. Similarly, there is no identifiable group of intravenous drug users, since much drug use is casual, occasional, hidden or experimental.

Many people at higher risk of infection attend sexually transmitted diseases clinics. It has been suggested that testing for HIV should be actively encouraged or made mandatory for all who attend these clinics. However, these clinics have important dual roles. They provide expert diagnosis, counselling and treatment for attending patients, and also the most useful information on sexually transmitted diseases for monitoring public health. Attendances at these clinics need to be encouraged, and the disadvantages in

using them for mandatory testing to monitor HIV infection would need to be carefully considered.

Testing to minimise perinatal transmission

Routine antenatal testing of pregnant women in most developed countries already includes taking and testing blood specimens for blood groups, blood group antibodies, haemoglobin levels, and often for certain infections such as syphilis which could adversely affect the pregnancies and babies. The question of whether pregnant women should be tested for HIV along with these other routine tests has been raised. Because of the ethical issues involved, it would be desirable to establish a public and preferably uniform national policy about such testing.

In developed countries and in many developing nations pregnancy is becoming increasingly a matter of parental choice and conscious decision. There is an increasing acceptance of voluntary pre-pregnancy testing for genetic and infectious diseases which may be transmitted to children before birth.

As long as the prevalence of HIV infection in the general Australian population remains very low, governments could inform parents about HIV testing and leave them to make up their own minds freely about whether and when to be tested. However, if HIV becomes more prevalent in the general population it may become desirable for governments to promote voluntary pre-pregnancy testing more actively.

Possible policy components

- Provide voluntary testing for anyone wishing to be tested.
- Actively and widely encourage voluntary testing.
- Test the whole population on a compulsory basis.
- Test people believed to be at higher risk of infection on a compulsory basis.
- Test pregnant women or women considering pregnancy, with specific consent.
- Test pregnant women or women considering pregnancy, without specific consent.
- Following a positive test, minimise transmission by:
  - providing counselling and education in order to encourage appropriate behaviour change;
  - quarantining infected people;
  - excluding infected individuals from particular activities.

3.3.2 Contact tracing

Contact tracing is a standard means of managing the public health aspects of infectious diseases. In practice, contact tracing has been of limited benefit in the management of sexually transmitted diseases. The varying incubation period of HIV-related disorders may make it even more difficult.

For small, relatively closed, sexually active or intravenous drug taking communities, educational campaigns based on the assumption that most or all people have been in contact with an HIV-infected person may be a more effective public health measure. However, in most cases contact tracing can help limit further spread of infection and allow those infected to make decisions about their life.

Identification and notification of those who may have been placed at risk of infection is normally undertaken by the infected individual, who may request assistance from primary caregivers. Most diagnosed people with HIV are undertaking their own contact tracing and this should be widely encouraged. Occasionally, contact tracing is conducted by trained members of government agencies, in a confidential and sensitive manner, and with the consent of the individual.

The responsibility for contact tracing should be discussed during pre-test counselling. The person seeking testing should be made aware of the types of contacts that need to be identified and the period during which infection may have taken place. The person should indicate whether they have a preference for undertaking the contact tracing personally or whether they wish to seek the assistance of another person. If dealt with during pre-test counselling, a refusal to warn sexual or needle sharing partners can be addressed at an early stage.

Ideally, the infected people themselves will contact others at risk of infection from their actions. This cooperation is an effective form of contact tracing, but it requires help with the skills needed to discuss the issues, to inform the contacts accurately about HIV infection and to be able to provide information on available services. Follow-up is needed to ensure that those who agree to notify their contacts have done so.

However, infected individuals are often reluctant to carry out the contact tracing and may seek to put the responsibility on a general practitioner, staff in AIDS, STD or outpatient clinics, social workers, counsellors, community health workers or outreach workers.

Contact tracing may also be carried out by public health authorities, but this may be a less desirable option if doubts exist about the use to which such information could be put. This is particularly so where behaviours involved in HIV transmission are illegal. Whenever contact tracing is carried out by someone other than the infected individual, specific consent should be

sought for the tracing, and the name of the infected person should be kept confidential.

It has been suggested that, in the event of a positive HIV test, routine or compulsory notification of sexual partners should be required, particularly if the person infected refuses to do so voluntarily. The dilemma facing health care workers or public health officials in this case is the obligation of confidentiality towards the infected person, and the obligation to protect a third person. It is preferable to resolve such situations on a case by case basis through counselling rather than by legislation. It is likely that people would be reluctant to present themselves voluntarily for testing knowing that the results of such a test would be routinely passed to anyone perceived to be at risk of infection from them.

Possible policy components

- Place responsibility for tracing sexual or needle sharing contacts of a known infected person with:
  - the infected person, after counselling on how best to do it;
  - primary caregivers;
  - public health authorities.
- Notify, either on a compulsory or discretionary basis, those perceived to be at immediate risk from a known infected person.

3.3.3 International travel and immigration

The rapid global spread of HIV is linked to the mobility of modern travellers. Regular reviews of current policies on international travel and immigration are required to assess whether they are consistent with containing the spread of the virus.

Governments need to consider each of the policy components in terms of their effectiveness, the costs and benefits of their introduction, practicality, and human rights and international diplomacy issues.

Other measures to contain the spread of infection include HIV education aimed at travellers and immigrants before they arrive in Australia, and wide dissemination of safer behaviour guidelines to Australians departing the country.

International travellers

Calls for routine HIV testing of international travellers, and, more particularly, of immigrants and long-term visitors, have been made from time to time. A WHO Consultation on International Travel and HIV Infection, held in March 1987 to examine this issue, concluded that screening programs for international travellers would, at great cost, retard

only briefly the dissemination of HIV both globally and in any particular country [WHO 1987].

Screening of international travellers will not prevent HIV infection coming into any country. The HIV antibody test, with its time lag of up to three months after infection, means that anyone infected during that period may test as negative.

Testing all incoming travellers would generate significant costs for the governments and for travellers. There would be a negative impact on tourism, particularly if travellers were asked to bear the cost of testing. Many, such as the elderly and children, would be at low risk. Others, such as diplomats and members of religious orders, would expect to be exempted. All returning Australians would have to be tested, to ensure that they did not bring infection from their travels, and to avoid inconsistency. The possibility of substitution and false certification would always be present. Testing would have to be done at the place of embarkation, as testing on arrival would be impractical.

To eliminate false positive results, follow-up testing would be needed, so testing could take a number of weeks. There would be clear difficulties in refusing entry in all circumstances, especially for tourists, until a positive test result was finally confirmed.

The costs, inconvenience and political problems of testing all travellers must be weighed against the marginal impact that such a measure would have in limiting the spread of HIV infection in Australia.

Limiting testing to people from known high prevalence areas would cut down total testing numbers, but would still present practical difficulties. Identifying high prevalence areas on the basis of reported AIDS cases penalises people from countries with well-established reporting systems and may ignore others from countries that do not. Identification based on estimates or hearsay would be even more haphazard and politically contentious. Even if all people from cities with relatively high rates of HIV infection, such as New York or Paris, were nominated for testing, their relative risk of having HIV infection would still be small. The most likely result would be a cut in tourism to Australia.

It would not be logical to test people from certain geographic areas unless all Australians who had visited the same areas were also tested on their return. Since Australia has the highest HIV prevalence rate in the Asian-Pacific area, other countries in the region would have more reason to impose testing on Australian tourists than Australia has to test incoming travellers. Screening nominated risk groups on the grounds that they may be infected, also appears impractical, for it relies on voluntary identification by members of those groups. There are obvious disincentives to this identification, and it is unlikely that the policy could be made to work.

The WHO position that certification and testing of international travellers is not warranted has guided Commonwealth Government policy in Australia.

Immigrants

Current Commonwealth Government policy on immigration is that there is no routine HIV testing program for potential immigrants. As part of the medical examination undertaken by all immigrants, specific questions are asked about previous higher risk behaviour, such as male to male sexual activity, and possible exposure to HIV, for example through receipt of blood or blood products. Examining doctors also check specifically for clinical signs such as evidence of intravenous drug use or enlarged lymph nodes.

On the basis of an affirmative answer to any of the relevant questions, or any clinical indications from the medical examination, the doctor could request that the applicant give consent for an HIV test. If a person is found to be infected the Department of Community Services and Health would normally advise the Department of Immigration, Local Government and Ethnic Affairs (DILGEA). This advice would be one of the grounds on which a final decision would be made by DILGEA.

Arguments for screening immigrants and long-term visitors rest on two propositions. The first is that an infected immigrant may infect others after arrival in this country; the second is that an infected immigrant will be a burden on public health and welfare services.

Testing of all immigrants to cut down the spread of infection, while not testing all travellers, would not be consistent, for there are many more people returning to Australia from holidays or business trips, and visiting tourists and business men, than there are immigrants.

For an Australian to become infected with HIV from an immigrant, he or she must engage in risk activities. The hazard is not the immigrant, but the risk activity itself. The question of testing must therefore be assessed on the basis of its potential to save future costs on the public health and welfare systems.

The direct costs of testing could be borne by the Australian Government or by prospective immigrants. These costs include the cost of all HIV tests, the cost of transporting blood samples to approved laboratories and counselling costs. There would also be substantial personal expense for immigrants associated with the consequences of test results.

It would be essential for the Australian Government to establish an effective quality control program for overseas HIV testing and to develop and implement an HIV counselling training program for panel doctors.

There are a number of practical problems associated with maintaining a high level of quality control of testing. There are possible legal problems

with confidentiality of results, and concern with the consequences of inadequate counselling would need to be addressed.

A full analysis of the costs and benefits of testing all immigrants would also need to take into account a balancing of the political costs of such a program and, in some cases, the economic contribution provided by infected immigrants, against the loss of economic productivity if and when they fall ill. These costs are practically impossible to quantify.

Screening immigrants selectively could be examined on a geographic basis, or for specific groups, or a combination of both, involving much lower costs and with a higher prospect of identifying HIV-positive applicants.

There will still be some difficulties. These are substantially the same as those for screening all travellers from nominated areas or groups, including the likelihood of people from particular groups failing to declare themselves to immigration officers, and the diplomatic consequences of singling out particular countries.

Refugees

The policy of the United Nations High Commissioner for Refugees is that refugees should not be singled out as a group at special risk. According to this policy, no program or health intervention can be allowed unless it lies totally within the framework of the national AIDS program of the refugee-hosting country and applies to all residents and citizens of the country. This principle underlies all health services provided for refugees [UNHCR 1988].

Education of travellers

Education of travellers leaving, entering or returning to Australia is essential to a national prevention strategy. Those travelling overseas, whether as tourists, on business, or on long-term postings, should be made aware that they can place themselves and others at risk through their behaviour. For many tourists and people travelling on business the holiday romance, the business conference which includes after hours entertainment, or the casual sexual encounter, are regarded as short-term, minor aberrations, to be forgotten when the journey is over.

However, the global spread of HIV infection requires travellers to recognise that this is risk behaviour. There is already at least one Australian case of a businessman acquiring HIV infection in another country in this manner, and passing it to his wife. Furthermore, Australian travellers could be held responsible for the spread of the virus especially to countries in our immediate region.

Few studies have yet been undertaken of seroprevalence levels among male or female prostitutes or others in the Asian and Pacific regions. However, there are indications that the virus is present in these groups in most, if not all, of these countries. In parts of Europe and the United States, high

seroprevalence levels also exist amongst drug users and their sexual partners.

While there is still a possibility in some countries that infection could result from a transfusion of infected blood or from the medical use of an unsterile needle, the greatest risks to travellers are infection as a result of sexual or needle sharing behaviour. The WHO Global Programme on AIDS has prepared an information booklet for travellers which discusses risk factors and provides guidelines for preventing infection. The Australian Government distributes it to all travellers leaving Australia. A health leaflet is already distributed to each person entering Australia which lists the behaviours and situations which place people at risk of infection and provides telephone numbers and addresses for information, counselling and testing services throughout Australia.

Incoming travellers need to be made aware that, if they have become infected, they could pass the infection on to others. The sexual partners of overseas travellers need also to be aware of this risk and to take appropriate measures to protect themselves.

Education aimed at travellers could include:

development of suitable materials, including airport posters, inflight audiovisual messages and printed material;

support and cooperation from the travel, tourism and hospitality industries, and organisers of special events;

support and cooperation from key government departments; and

active media support, especially from editors of airline and travel magazines, "what's-on" directories, and from travel writers.

Preventing further spread through these measures can be assisted if they are actively pursued by governments with the cooperation of the travel industry.

Possible policy components

- Continue current Australian policy whereby prospective immigrants, refugees and longer-term temporary entrants are asked to consent to HIV testing only if it is clinically indicated or as a result of specific questions relating to risk of HIV infection; a positive HIV test result is a cause for recommending rejection on health grounds.
- Test all entrants to Australia for HIV, or test selected groups or people from geographical areas known to be associated with high levels of HIV, with, following a positive test:

  - automatic exclusion;
  - review of applications on a case by case basis.
- Educate all travellers leaving, entering or returning to Australia about transmission of HIV.

3.3.4 Procedures following death

Procedures adopted for handling bodies or arranging funerals must be designed to minimise any occupational risk of infection.

However, there has been considerable distress as a result of procedures adopted for the handling of bodies or arranging funerals. Public health regulations have imposed severe restrictions. In New South Wales the bodies of people who were known or reasonably suspected to have been HIV-infected, or to have had an HIV-related condition at the time of death, may not be made available for viewing. At death they must be sealed in plastic bags by staff wearing disposable infection control clothing.

There is no scientific justification for such extreme restrictions. In many cases, great distress is caused to family members and friends; the needs of some communities, for whom farewelling the body is an essential part of the funeral service, are ignored.

Rational, scientifically based procedures without undue restrictions should be adopted for the handling of all bodies, ensuring an appropriate balance between the rights of employees and the needs of the family and friends of the deceased.

All non-cremated remains, whether bodies or tissues, imported into Australia, should be treated as potentially infectious.

Possible policy components

- Develop uniform and sensitive guidelines for handling HIV-infected bodies and for funeral arrangements.
- Treat all non-cremated human remains imported into Australia, whether bodies or tissues, as potentially infectious.

3.3.5 Condom standards and availability

Rubber condoms, when properly used, have been shown to be effective in reducing the risk of transmission of HIV.

Restrictions on the availability of suitable condoms should be removed, and adequate standards and manufacturing quality controls strictly maintained.

Condoms can be used to prevent contact with body fluids during sexual activity. Semen, vaginal fluids, anal fluids, blood and possibly saliva may contain the HIV virus. Two way protection is required from the beginning of sexual activity until its completion, and the user must use the condom correctly for that protection.

Currently, Therapeutic Goods Orders (TGO) No. 31 requires all rubber condoms, including imported rubber condoms, to comply with Australian Standard (AS) 1919-1985. This means it is illegal to market condoms of poor quality or with no expiry date on the condom packet. Condoms contravening TGO 31 may be recalled.

The Australian Standard 1919-1985 specifies two tests: air inflation, and freedom from hole (water leakage) tests. These appear to be suitable to determine the reliability of rubber condoms as a contraceptive device and a barrier for sexually transmitted disease in heterosexual intercourse. However, there is no evidence to show that the tests are suitable for determining the reliability of condoms as a HIV barrier, or for use during anal or traumatic vaginal intercourse. Most manufacturers also test electronically each condom for holes as part of their manufacturing process.

Ageing of condoms is not addressed in Australian Standard 1919-1985. The Australian Standards Association is looking at this issue and it may be included in a review of the Standard.

Natural membrane condoms and novelty condoms or sexual aids are not regulated under TGO 31. Novelty condoms are required to be boldly labelled, indicating that they are not suitable for contraception and infection control. If not so labelled they are subject to all the requirements of TGO 31. Consideration could be given to banning any condoms which are not suitable as an HIV barrier.

Guidelines for instructions on condom packets have been addressed by Australian Standard 1919-1985, Clause 11. Such guidelines were established by industry, consumer advocates and health authorities, Commonwealth and State. TGO 31 requires these guidelines to be followed.

Much condom failure can be attributed to incorrect or misunderstood use, so instruction on their use and the use of lubricants is important. Instructions should be simple, given the limitations on the amount of information that can be included in a condom packet and how much of it is likely to be read. As oil based lubricants such as vegetable oil or petroleum jelly can cause weaknesses in rubber condoms, the requirement to use water based and silicone lubricants must be clearly stated.

One strategy may be to produce a set of standard instructions and warnings which, like cigarette packet warnings, are rotated frequently. This could be supplemented by more detailed leaflets, in various languages, made available much more widely than at present, including in schools, venues

frequented by young people, conference and convention centres, needle exchange and other drug programs, community health centres and brothels.

It has been proposed that condoms for anal intercourse may need to be stronger than other condoms and that appropriate warnings be provided about the suitability of particular condoms for particular sexual activities. A wide range of sexual activities may test the durability of condoms and this should be taken into account in setting condom standards. One problem with separate standards for condoms intended for use in different ways is that it would not be sensible to assume that partners indulging in one form of sexual activity would not also engage in another.

The efficacy of condoms as protection from HIV infection is dependent on the adequacy of the Standard which should be reviewed in the light of changing patterns of use.

The widespread retail availability of inexpensive condoms is important to the control of HIV. Outlets that are easily and commonly frequented by the public are important and any limitations on the sale or distribution of condoms should be removed.

Possible policy components

- Review the standards that apply to rubber condoms for adequacy as a barrier to HIV.
- Apply these standards to all condoms.
- Ban condoms unsuitable for use as an HIV barrier.
- Remove limitations on the availability of condoms.
- Produce and label condoms to specify use for particular sexual activities.

3.3.6 Compulsory treatment

Historically, treatment has been required or recommended for a few communicable diseases to reduce or eliminate the risk of infection to others. Tens of thousands of Australians with tuberculosis were treated after a nationwide compulsory chest x-ray programs in the 1950s and 1960s.

There are reasons against compulsory treatment of HIV-infected people. Unlike tuberculosis, HIV is not a contagious, airborne infection. Infection is for a lifetime since there is no safe and effective treatment which will cure infection. More importantly, there is no treatment available which reduces an infected person's infectivity.

In such circumstances, compulsory treatment is not an appropriate public health measure.

Possible policy component

- Consider compulsory treatment for HIV infection if it can be shown that treatment reduces infectivity.

3.3.7 Immunisation

A vaccine for HIV infection is not expected to be available in the time frame of this strategy. Even if a vaccine were developed, it could not be released for widespread use until adequate trials had taken place. Prudent basic principles relating to the development and manufacture of biological products, vaccine safety, effectiveness and strategy evaluation will need to be observed.

Nevertheless, Commonwealth, State and Territory governments could consider planning for a national HIV immunisation program, identifying priority groups to be immunised, with their logistic and education requirements. Decisions will be needed on whether immunisation should be compulsory or recommended and whether for the whole population or limited to selected risk groups. Health authorities could also prepare for the effect of immunisation on HIV testing methods and the national monitoring of HIV infection.

Possible policy component

- Plan in advance for a national HIV immunisation campaign.

3.4 The role of the law

3.4.1 The role of the law in minimising transmission of HIV

The law has a role to play in minimising transmission of HIV by complementing and supporting education and prevention programs.

The spread of HIV has raised a range of issues for the legal system, including the role of criminal law, protection from discrimination and breaches of confidentiality, and laws relating to occupational health and safety.

As the number of reported AIDS cases continues to rise, there may be increasing pressure on governments to use the legal system to enact punitive or restrictive measures. A number of legal responses have been suggested including universal or selective testing, closure of gay venues, criminal penalties for transmission, compulsory notification of HIV infection, and restrictions on freedoms of infected people through limitations on employment, quarantine or compulsory detention.

Governments will need to determine the likely effectiveness of such legal measures in minimising HIV transmission, and consider means to protect the rights of both infected individuals and the community.

Examination of the role of the law should include consideration of existing laws relating to public health management of infectious diseases. Such an examination was recently undertaken in Victoria where amendments have been made to the Health Act, including legal requirements for counselling when testing and notifying test results, protection of confidentiality of test results and protection from discrimination.

Public health legislation contains restrictive measures and accords extremely wide powers to public health officials. For example, legislation in South Australia prohibits people with an infectious disease from entering a public library or using public transport without notifying the driver. Some of these laws deserve legal review in general and as they relate to HIV.

Possible policy components

- Limit the role of the law to complementing and assisting education and prevention programs to minimise transmission of HIV.
- Public health related legislation to be reviewed by governments which have not already done so, including reassessment of the wide powers accorded to public health officials in legislation governing the control of notifiable infectious diseases.

3.4.2 Legal impediments to prevention programs

Laws penalising homosexual activity, prostitution and drug use may impede public health programs designed to deal with HIV infection. The question should be raised as to whether, on public health grounds, these laws should be changed.

The criminality of these acts may jeopardise public health measures to prevent HIV transmission, by driving underground many of the people most at risk of infection.

They potentially prevent or hinder government and community action to work against the further spread of HIV and may create conflicts in law between areas of government. As long as these offences exist, anyone who aids or abets in soliciting for prostitution, engaging in homosexual acts or possessing injection equipment for drug use may also be guilty of an offence. This can place health workers, counsellors and educators in possible conflict with the law and may create suspicion or hostility, rather than trust, between people at risk and authorities.

Laws relating to censorship and broadcasting standards

Presentation of facts about HIV transmission in the electronic and print media has only rarely caused legal problems because of a general recognition that HIV demands a frankness of approach going far beyond community norms of only a few years ago. Some television messages have been run later in the evening than campaign planners had intended, and some radio messages have been refused, not because of legislative requirements so much as proprietors' or broadcasters' concerns over offending their audience.

However, laws relating to censorship and broadcasting standards need to recognise that material about minimising HIV transmission may need to be explicit to be effective. A review of censorship laws and of radio and television broadcasting standards may be needed. Hearings to discuss appropriate changes could assist in countering any reluctance of broadcasters and other personnel.

Possible policy components

- Examine laws penalising homosexuality, prostitution and use of injection equipment to remove legislative impediments to preventive programs.
- Identify ways in which preventive programs and policies could be implemented within existing laws.
- Review laws relating to censorship and broadcasting standards.

3.4.3 Knowingly transmitting the virus

Ways in which a person may knowingly place another at risk of infection with HIV include having unprotected sex with that person, sharing injection equipment, failing to follow known infection control procedures, or attacking the person in order to infect them.

A person thought likely to transmit the virus knowingly could be subject to legal penalties and sanctions or could be assisted to change their behaviour. This assistance could take the form of education and counselling or referral to a community based program designed to provide support and guidance to such people.

Provisions in public health legislation in Victoria and Queensland make it an offence knowingly to infect another person with an infectious disease without their knowledge and consent. In New South Wales it is an offence under the Public Health Act for a person with a proclaimed disease to engage in sexual intercourse with another person without their informed consent on the matter of the disease.

It is unlikely that such offences, even with severe penalties, will be effective. There are major difficulties in proving beyond reasonable doubt that one person infected another with the virus, or that a person had prior knowledge of infection but did not take precautions to protect others. Imposing jail sentences would merely transfer the problem to another environment, and should only be considered when all other avenues have failed.

There is a clear distinction between transmission with intent, and transmission through negligence. Under criminal law there are offences of intentional infliction of grievous bodily harm, and common and aggravated assault, and the common law provides for damages for assault. In cases of transmission through negligence, the criminal law provides for offences where the negligence is found to constitute gross or criminal negligence, and the common law provides for damages in an action for negligence. However, neither would be easy to prove. The law applies to health care workers who may through negligence infect a patient.

Criminal law prosecution or common law damages actions will provide little comfort to those who have acquired HIV infection through intent or negligence, or to their families. A far better response to such situations is to plan against their arising.

Personal education and counselling of a person thought to be likely to transmit the virus could be ordered under public health legislation, on the decision of an authorised person such as a Chief Medical Officer of a State Health Department. Alternatively, the authorised official could refer the person to a community organisation for support, counselling and guidance. Education, support and counselling to change behaviour should be fully

explored before any person is subjected to legal penalty, or the powers of quarantine or detention which are currently provided to public health officials under State or Territory legislation.

Addressing the problems arising when infected individuals refuse to take precautions to limit the spread of HIV should be considered at a national level in consultation with relevant health departments and legal jurisdictions. An approach based on education, counselling and community group support is more likely to be effective than reliance on penalties or the threat of legal sanction.

Possible policy components

- Impose legal penalties for knowingly transmitting the virus.
- Isolate infected people thought to be knowingly running the risk of infecting others.
- Educate and counsel on a personal basis infected people thought to be knowingly running the risk of infecting others.
- Involve community groups in support measures, counselling and guidance.

3.4.4 Education of workers in the legal system

HIV-related matters will increasingly be brought before the legal system. These matters may often be complex and may present issues for which there are no precedents.

Education programs on HIV for all legal system workers are highly desirable. Many cases will arise out of a fear of infection and so it is important that legal workers understand the facts relating to transmission and infection control. They also need to be conversant with the issues relating to testing, confidentiality, defamation and discrimination and to be aware that these matters will elicit the same range of emotions in the legal community as they do in the general community.

Possible policy components

- Establish a regular and frequently updated system of information about HIV for legal system workers.
- Develop programs for the education of legal workers on a national basis.

3.5 Prevention strategies for priority groups

3.5.1 Homosexual and bisexual men

The spread of HIV among homosexual men has been reduced but it has not been halted. There has been less success among bisexual men. More work is needed with both groups.

Acknowledged homosexual and bisexual men

Homosexual and bisexual men remain a high priority group for prevention and education programs. It has been estimated that between 5 per cent and 10 per cent of adult males are exclusively or predominantly homosexual, giving a national figure of approximately 250 000, with a substantially larger figure of men who have sex at least occasionally with other men but who do not identify as homosexual [Ross 1988].

It is possible that the figure is higher. In 1982 the New South Wales Anti-Discrimination Board's report on Discrimination and Homosexuality reviewed the available research and concluded that at least 10 per cent of the adult male population of Australia is exclusively or predominantly homosexual.

Early education efforts, based in the gay community, have been very successful in disseminating information, encouraging behaviour change and developing peer support for the adoption of safer behaviour, especially amongst those who identify as part of this community. Constant reinforcement of messages through the gay community, and extension to all groups of homosexual and bisexual men, will be needed to continue and sustain behaviour change.

However, there are still substantial numbers of homosexual men who do not consistently practice safer sex. These include men for whom English is a second language, men with low literacy or other communication disabilities, poor self-image, lack of peer support, lack of identification or contact with the established gay community, and those who use alcohol and other drugs at risk levels.

Education is the principal strategy for reducing HIV transmission among homosexual men and continued funding of those organisations already skilled in delivering programs is important. However, reliance solely on gay organisations to educate homosexual men will not be effective in reaching those men who do not identify with the gay community.

Public education programs need to recognise that homosexual men are part of our society. They are in employment and in educational settings, in rural

as well as in urban areas, and as diverse in other socioeconomic characteristics as the rest of the population. Homosexual men can be reached by programs aimed at the general public.

Homosexual men also use the same range of health, education and welfare services as the rest of the population. So information about unsafe homosexual activity as well as unsafe heterosexual activity should be part of school, university and health service based programs.

Homosexual intravenous drug users are, according to current anecdotal findings, predominantly occasional users of drugs like heroin, cocaine and amphetamines. Access to this sub-group is likely to be best achieved through peer education and outreach programs which can operate within gay entertainment venues and through the established street networks. These may also be the most appropriate access for educational efforts aimed at homosexual men working as prostitutes.

Some studies in the United States suggest that casual use of alcohol and other drugs may have a negative impact on the consistent practice of safer sex. Programs aimed at educating homosexual men about the dangers of using alcohol and intravenous drugs may also prove valuable in preventing the spread of HIV.

Some homosexual men are also dependent intravenous drug users, and strategies should be directed at them through drug programs as well as through the gay community. Such men constitute an important bridge between the two groups currently at higher risk of HIV infection in Australia and may be at increased risk of both transmitting and becoming infected with the virus.

In Queensland, Tasmania and Western Australia, homosexual activity between adult males is still illegal. While the consequences of admitting to homosexual activity, or of consulting a gay advisory service, could entail criminal prosecution, harassment or social stigmatisation, there will continue to be a reluctance on the part of many homosexual men to be open about their sexual preference. This appears likely to act as an impediment to education programs or to their seeking information or advice on unsafe sex.

So it will be important to the prevention of HIV that these States and Territories reconsider such legislation. If it stands in the way of the maintenance of public health, legislative amendments may be required as a matter of some urgency.

The availability and acceptability of condoms also needs to be considered in the strategy for preventing HIV among homosexual men as well as among other groups. AIDS organisations distribute many thousands of condoms free of charge at large public events and through outreach programs. However, condoms are often not readily available in hotels and clubs or shops other than pharmacies.

Strategies to increase the number of condom vending machines, particularly in entertainment and leisure venues, and to increase the distribution and sale of suitable condoms through a variety of commercial outlets need to be considered. Such strategies could take the form of a cooperative effort between condom manufacturers, governments, hotel and entertainment proprietors and supermarket operators in both the widespread distribution of condoms for sale and in the marketing of condoms through the mass media.

Other men who have sex with men

Many men who have sex regularly or occasionally with other men do not identify as homosexual or bisexual and may have no ongoing contact with gay health, education or entertainment services. They are likely to have little personal experience of the effects of HIV on friends or acquaintances. They are especially hard to reach with messages about HIV prevention, and may well be at increased risk of infection because of this isolation.

The sometimes hidden nature of homosexuality and bisexuality, especially among married men, presents very real challenges for the education strategy.

It is often very difficult for bisexual men to acknowledge to female partners the sexual relationships they have with other men. Bisexuality is not widely discussed in the media or in education programs and there appears to be little community understanding of it or of its extent.

In spite of the advent of HIV and the risks of infection, it has proved difficult for some bisexual men to start using condoms or to adopt other safer sex techniques with their female partners, since such a change might entail discovery of their sexual activities with men. These men need to be informed of the risk to their female sexual partners, and the risk of passing the infection on to any children they may have.

Some programs have begun to reach and educate bisexual men. Continued funding to organisations like the Gay and Married Men's Association (GAMMA) and widespread promotion of its services will be important to ensure some avenues of counselling and information for those not reached through the gay organisations.

It is necessary to increase public understanding of bisexuality. Bisexual or gay and married men may be reached through any medium of education which is appropriate for the heterosexual population. Programs are urgently needed to reach the female sexual partners of bisexual men.

Mass media advertising and articles in family and women's magazines and newspapers will be important in disseminating information and improving awareness of this little understood aspect of human sexuality. The sensitivity of the topic will require delicate handling and will almost

certainly benefit from consultation with people from the target audience to determine the most appropriate and powerful form for educational messages.

Education about bisexuality for health, welfare and education workers will play an important part in preventing further transmission both to and from bisexual men. This will apply especially to those in such areas as family therapy, marriage guidance and family planning services and training in counselling about HIV prevention.

The prevalence of bisexuality in the Australian community is not clearly known, and further research in this area would provide much needed guidance for the development of prevention programs.

Possible policy components

- Extend, monitor and evaluate education and prevention programs aimed at homosexual and bisexual men.
- Extend urgently education and prevention programs designed to reach homosexual and bisexual men who are not part of the gay community.

3.5.2 Needle sharing drug users

Drug users who share injecting equipment must become a high priority group for HIV education and prevention programs. Experience overseas shows that, with effective prevention programs, the risk of transmission within the group can be minimised significantly.

Almost all intravenous drug users report sharing injecting equipment at some time or another. Although there is little research available about the motives for or the circumstances of sharing, one study from San Francisco suggests that the behaviour is largely situational, resulting from shortages of equipment, impulsive use or the sharing of a collective drug purchase with sexual partners and close friends [Murphy 1988]. For regular users, sharing may serve economic, social, cultural and secrecy needs. Sharing is very common among ex-users who relapse, since this is often unpremeditated.

Intravenous drug users are particularly hard to reach with education or preventive messages. They do not form a homogeneous group and apart from their injection of illegal substances, individual users may have little or nothing in common.

The very illegality of the behaviour ensures that it often remains hidden, even from those who know the individual well. Acknowledgement of the behaviour can entail stigmatisation and loss of employment, civil liberties or relationships. Few ever come into contact with conventional drug treatment services.

All governments need to consider and act immediately upon the options available to minimise the risk of transmission among intravenous drug users and urgently introduce appropriate programs.

Increasing the availability of injecting equipment

Politicians have courageously initiated needle and syringe distribution and exchange schemes in many parts of the country. Given the trends in the United States and Europe of increasing infection among intravenous drug users, those authorities which have been hesitant to introduce needle and syringe exchanges should be encouraged to review their position.

One of the principal strategies available now for preventing HIV transmission is expanding these programs and removing legal sanctions against possessing or using equipment to inject illegal drugs in all jurisdictions. The increasing availability of sterile equipment has already achieved some behaviour change among regular and dependent users.

The Ministerial Council on Drug Strategies and State Attorneys-General may need to consider developing of a consistent approach to distributing injecting equipment. This may well require community education to increase public support for such measures.

Outlets for selling or distributing sterile equipment need to be increased and dispersed. Mobile units, like the AIDS buses operated in the inner city of Sydney and in Canberra, can take needles and syringes, condoms, and information about HIV to users. This may be the only way to reach intravenous drug users in outlying areas, or districts where public transport is poor.

Access to clean needles and syringes is effective in minimising HIV transmission, and in bringing many users into contact with health and education workers who can provide additional assistance for drug use problems.

One option for reducing the sharing of equipment is to distribute syringes which are not capable of reuse. The production of such equipment is still in the developmental stage, but if successful, these syringes could replace reusable ones.

Legislation to ban the manufacture or importation of multiple use 1 ml and 2 ml syringes and to support only the manufacture of single use syringes may need to be considered when single-use syringes are available, to ensure their widespread use.

Education about the decontamination of used equipment

While avoiding sharing equipment every time is clearly the preferred option, education about the decontamination of used equipment is also required.

The use of bleach for decontaminating needles and syringes has been widely promoted in San Francisco where sterile needles and syringes are not readily available, and appears to have slowed the rate of HIV infection among intravenous drug users.

Information about cleaning equipment has been given some coverage in HIV prevention programs in Australia, but not consistently. This has led to confusion about the appropriate technique to be used.

While there is some concern about the use of bleach, the provision of consistent and accurate information about cleaning procedures can help in reducing the risk of HIV infection where sterile needles are not available or to hand.

Drug treatment services and other alternatives

Intravenous drug use can be reduced through at least two strategies: by attempting to change the route of administration of drugs currently used intravenously, or by drug substitution.

Existing methadone programs aim to substitute orally administered methadone for intravenously administered heroin. Places in these programs for dependent heroin users may be a significant measure in HIV prevention. However, methadone maintenance treatment is not appropriate for non-dependent opioids users, or for people who inject substances other than opioids.

A number of drugs currently used intravenously could be taken in other ways: by smoking, snorting or by mouth. Some limited success has been achieved in the United Kingdom with programs directed at changing heroin administration from injection to smoking. However, because of the low strength of heroin available in Australia there is almost no tradition of heroin smoking here. Consideration could be given to introducing experimental programs to initiate change amongst regular and occasional heroin users.

Many regular intravenous drug users would not be prepared to take drugs by any other means. Consideration could be given to experimental programs providing intravenous methadone or heroin in single use syringes, with safeguards against the leakage of drugs from such programs to the black market.

Legislative review

There are three areas of preventive activity which require a review of legislation. The first, discussed above, relates to reducing needle sharing by increasing the availability and supply of sterile or single use syringes.

The second relates to the difficulty of reaching people with education when their activities are illegal and discovery entails considerable penalties. Consideration could be given to decriminalising possession and use of small quantities of illegal drugs for personal use to encourage more people to be open about their activities and so be reached by education.

Decriminalisation would also assist in keeping large numbers of drug users out of gaol, where the risks of HIV transmission are considerably greater because of the lack of sterile injecting equipment or condoms.

Thirdly, repealing laws which make some drugs illegal would allow the implementation of programs which aim to change the method of administration from intravenous use to smoking or snorting. Government authorities may wish to consider the merit of reviewing these laws.

The role of conventional drug treatment agencies and workers

Research has shown that many people stop using drugs or recover from their dependency without ever attending a formal drug treatment program. However, they may have sought treatment or advice for drug related problems at a variety of health services, including general practitioners, hospital casualty, inpatient, accident and emergency units, and social welfare services. Others may participate in treatment programs many times before finally achieving life long abstention. Others are confined in prisons and other correctional institutions where their drug problem may or may not receive adequate attention.

Workers in any of these settings could become educators about safer behaviour. This would require the training of health and other service professionals, including drug treatment workers.

For some professionals, this will be difficult both personally and occupationally. Where a drug treatment service has a commitment to abstinence, the concept of minimising harm by teaching needle cleaning or by providing information on needle outlets can present a significant conflict.

Specific skills training programs could assist drug workers to work through such conflicts to support a strategy which aims to reduce both the immediate harm from HIV and the long term harm of continued intravenous drug use. These training programs would require the support of State and Territory health and drug and alcohol authorities.

Public education about needle and syringe sharing

Intravenous drug users do not form a homogeneous group within our society and their drug using behaviour may remain hidden for years. Advertisements on television, in magazines, in schools, on posters and billboards or in doctors' surgeries will be seen and heard by users. Casual drug use, especially among young people, has gained little public attention in the past. HIV prevention is going to require considerable candour.

It is a matter of priority to alert the public to the dangers of even a single occasion of needle sharing, and this is likely to require the use of appropriate mass media messages and other programs.

Peer education programs

Although intravenous drug users cannot be described as a community in the same way that the gay community is, they do have established networks of contacts and friends, and venues they visit regularly.

Similarly, former intravenous drug users may retain some contact with old user networks and are often seen as credible sources of information and advice by current users.

The use of peers as educators has proved very effective within the gay community. Further support is needed to establish groups of ex-users who can act as peer educators. This process is well advanced in some overseas countries and is achieving impressive results.

Telephone counselling and information services like ADIS (the Alcohol and Drug Information Service) and the AIDS hotline in Sydney need to be developed or expanded and widely promoted so that all States and Territories are adequately serviced with staff trained in HIV issues.

Support also needs to be given to community and government organisations which have the expertise to develop appropriate materials, messages and educational processes for drug users.

The role of other drug prevention programs

The Ministerial Council on Drug Strategy (MCDS) has considered measures that need to be included in drug treatment and prevention programs in the light of the need to prevent the spread of HIV infection.

The MCDS agreed that containment of the spread of HIV infection is a high and immediate priority which needs to be addressed in both the National Campaign Against Drug Abuse and in AIDS programs. The Council endorsed a range of measures within NCADA programs, including upgraded training, use of outreach workers and supporting research.

The goal of prevention of drug use need not be inconsistent with that of containing the spread of HIV. If fewer people use intravenous drugs, fewer are at risk of infection. The extent to which the relative importance of the goals needs to be considered will depend upon different circumstances and target groups for preventive programs.

Prevention of sexual transmission by drug users

There is evidence that intravenous drug users are rejecting messages about safer sex because they do not believe that they are at risk from sexual transmission.
Unsafe sexual activity amongst intravenous drug users occurs not only within loving relationships, but also for some in exchange for food, shelter, drugs, or protection. Whilst these exchanges are forms of prostitution, they may present much greater difficulties for the negotiation of safer sex than a straightforward transaction for money.

Education about the reality of sexual transmission for intravenous drug users is a priority.

Prevention of perinatal transmission by drug users

The best way of preventing perinatal transmission is ensuring that women do not become infected. Very high priority should be considered for drug treatment and intervention services for women drug users of child-bearing age or with children.

Disproportionately few women enter drug treatment programs or use drug and alcohol intervention services. Many programs do not accommodate their special needs, for example the accommodation of their children. Services which do so, such as Jarrah House in New South Wales, should be established more widely.

Women who are intravenous drug users, whether they are already pregnant or contemplating pregnancy, should be offered voluntary access to counselling and testing for HIV infection, abortion and priority access to drug treatment programs such as methadone maintenance.

Education programs for female drug users should emphasise that safer drug using and sexual behaviour is essential if they wish to have uninfected children.

Possible policy components

- Develop or extend urgently programs with the following objectives:
  - abstinence from drug use;
  - drug use without injection;
  - intravenous drug use without sharing;
  - sharing of only decontaminated injecting equipment.

- Extend needle and syringe distribution and exchange programs.
- Provide information on the cleaning of used equipment to intravenous drug users, particularly those who do not currently wish to enter drug treatment.
- Increase availability of drug treatment programs.
- Provide training courses for drug program workers and staff of other services in contact with drug users on issues arising from drug use transmission of HIV.
- Develop peer education programs to minimise transmission through sharing of equipment and through sexual behaviour.
- Include information about HIV in drug prevention programs designed for people at risk of being offered drugs.
- Continue to include occasional intravenous drug users in HIV prevention and education campaigns.
- Provide services and treatment programs for women drug users, including child care facilities, contraception and pregnancy counselling, and information on perinatal transmission of HIV.

3.5.3 Aboriginal and Islander people

Culturally specific and appropriate measures are needed to minimise HIV infection among Aboriginal and Islander people. These people, like other ethnic groups, are not at risk of infection as a group. However, education about the modes of HIV transmission and their prevention must be presented in languages, images, messages and materials that are familiar. Traditional Aboriginal concepts of disease, and Aboriginal learning and communication styles, differ from those of non-Aboriginal Australians. In particular, the credibility of a message for Aboriginal people depends on whether the person who brings it is known and trusted.

Policy decisions about sensitive aspects of traditional culture, if they are to be accepted, should be made by the Aboriginal community. Programs developed among groups with a common culture and language will be the most effective.

A number of extremely effective education and prevention programs have been started by agencies involved in health care delivery for Aboriginal people. Mobile outreach teams conduct programs in remote locations. Educational materials have been designed and condom distribution programs implemented.

Community members and Aboriginal health workers have usually been involved in the development and administration of these programs. The

success of such programs is often achieved by negotiating with each community so that audiences, messages and materials are agreed upon or worked out jointly. Increasing the number of Aboriginal health workers and ensuring they are familiar with the implications of HIV is essential, particularly since poor general health may act as a cofactor of infection.

The message on HIV infection to fringe dwelling and urban Aborigines will differ from that used with isolated communities. Urban Aborigines and Islanders will have access to information available to non-Aborigines, and while this may not be culturally specific it will have some impact. Material designed specifically for urban Aborigines and Islanders will be more relevant if developed in consultation with them.

In addition to education for prevention, both urban and isolated communities should be assisted to understand the needs of HIV-infected individuals.

Any policies adopted in this area could support and extend work already started, as well as assisting other Aboriginal groups and organisations to develop effective education and prevention programs.

Possible policy components

- HIV education and prevention programs to be developed by, or in consultation with, Aboriginal and Islander people.
- Improve Aborigines' and Islanders' health, in particular health conditions which may place them at greater risk of infection.
- Increase the numbers of Aboriginal and Islander health workers and train them in the implications of HIV infection.
- Develop education programs addressing the need for community support for HIV-infected Aboriginal and Islander people.

3.5.4 People in prison

Governments should consider their responsibility for minimising the potential of HIV infection among prisoners and staff, and between ex-prisoners and the community.

Overcrowding in Australian prisons is accelerating. At any time there are approximately 12 000 prisoners in the prison system. Drugs are available within prisons, and HIV positive people are passing through the prison system.

Awareness and fear of HIV infection has special connotations for the prison environment. Prison officers and prisoners have concerns over infected

needles being used as weapons, or as a means of coercion, and prisoners have long been concerned about institutional rape. The threat of HIV infection merely adds to these anxieties.

Education programs for prisoners and prison officers are important but will not have the desired impact unless they accompany other prevention measures which enable all prisoners and prison officers to develop strategies to protect themselves.

Prisoners and prison officers need to be closely involved in designing their own education programs using the direct language of the prison environment. A NACAIDS Working Group on Prisons recommended in 1987 that education programs rely on audiovisual presentations repeated frequently, involve prisoners, and use group discussion techniques. Programs imposed from outside will have little impact, especially if they are borrowed from a different environment.

Prisons provide an ideal opportunity to reach men and women, particularly drug users, who may be more difficult to reach on the streets. On release, they return to the community, taking HIV behaviour change messages with them.

Antibody testing in prisons is voluntary in Victoria, New South Wales, Tasmania and Western Australia, compulsory in South Australia, Queensland and the Northern Territory. The screening of approximately 12 700 prisoners in South Australia, Queensland and the Northern Territory between January and June 1988 identified 16 positive results, all from prisoners in known high risk groups.

All prisoners should have access to voluntary testing with counselling if they wish to know their antibody status. The testing could be done on entry, during their sentence and particularly before release.

Compulsory testing is logical only if it leads to measures to prevent transmission, such as segregation, needle exchange schemes and distribution of condoms. Some prison officers believe the two latter measures acknowledge and imply acceptance of illegal acts.

Opinion on segregating HIV-positive prisoners is divided nationally and internationally. Segregation is argued by some on the grounds that:

the virus poses a risk to other prisoners, through needle sharing or anal sex;

infection could be used as a potential weapon against prisoners or prison officers;

there is, based on fear, a risk of violence to HIV-positive prisoners; and

segregation allows specifically directed education and counselling to HIV-positive prisoners before release.

On the other hand many expert bodies, including the WHO Global Programme on AIDS, argue that:

HIV infection is not socially transmitted, and there is no reason to segregate HIV-positive prisoners, or to restrict their working in food preparation areas;

segregation may impose in practice a further penalty on a prisoner, through isolation;

it will inevitably attach a further stigma to prisoners; and

segregation makes antibody-positive status impossible to keep confidential, even after release from prison.

Needle sharing is the main risk activity for the transmission of HIV in prisons. Because of the high incidence of HIV infection reported by the Council of Europe in European gaols, especially amongst drug users, making needles available through anonymous exchange is being canvassed. Those in favour argue that, as with users outside prisons, those inside should have access to needle exchange, and that prisoners are being unfairly and dangerously penalised if they are unable to protect themselves in this way.

Those against needle exchange in prisons say it would condone drug use which, as an illegal practice, has contributed to many prisoners' sentences. They argue that drug use itself is the problem, and ought to be eradicated. Compulsory urine tests to detect drugs, followed by penalties such as loss of contact visits, have been suggested as alternatives to needle exchange schemes.

Similar arguments are made over whether condoms should be made freely and anonymously available. There are homosexual activities including rape in prisons. Arguments against free condom availability on the grounds that it would encourage homosexual acts are questionable and deprive prisoners of the ability to prevent sexual transmission.

The NACAIDS Working Group on Prisons recommended free condom and needle issue and, in the absence of needle exchanges, free issue of bleach for cleaning needles. These recommendations are supported by research showing successful implementation of condom distribution and needle exchange schemes in European prisons [Harding 1987].

In addition to the alternatives discussed there are a number of principles which relate to HIV in prisons:

prisoners should have access to the medical care and treatment that they would receive outside prison;

prison authorities should discourage discrimination by prisoners or staff against those infected;

confidentiality over HIV antibody status should apply with record keeping kept to a minimum; and

a prisoner's right to confidentiality after release should be maintained.

The threat of HIV spread within prisons and from there to the community is serious and warrants policy priority. A national effort drawing on Australian and overseas expertise is needed to reach agreement on appropriate prevention and support.

Possible policy components

- Introduce appropriate and specific HIV education and prevention programs for all inmates and for new inmates on arrival.
- Introduce education programs to educate prisoners on release about HIV transmission in the wider community and specifically in their own relationships.
- Introduce education programs, within the framework of employment training, for all prison officers.
- Provide access for prisoners to condoms, either by the introduction of condom vending machines or distribution by other means.
- Introduce needle and syringe exchange programs and/or distribute information and the supplies needed to decontaminate equipment.
- Provide access to methadone programs for intravenous drug using prisoners .
- Provide voluntary HIV testing for all prisoners, on entry, during their sentence and/or on release.
- Require compulsory HIV testing of all prisoners, on entry, during their sentence and/or on release.
- Segregate prisoners identified as HIV positive.

3.5.5 People in other closed institutions

Information on HIV transmission should be accessible to children, adolescents and adults in closed institutions in order to minimise potential infection.

Education and counselling for patients and staff of institutions and homes for psychiatric patients, disabled people, adolescents and children under

government care should be provided by State and Territory authorities and community groups.

A disability, whether intellectual or physical, does not normally deprive people of their sexuality or their related emotional needs. The possibility of sexual abuse by other inmates or by staff cannot be ignored. It is important that the facts about HIV transmission are easily available to occupants and staff, that condoms are freely available, and that inmates are assisted to protect themselves from HIV transmission.

To some staff and relatives of people in homes and institutions, the need for frank, sexually explicit discussion of HIV, and the availability of condoms will not be immediately apparent. However, administrators should, if necessary, override objections to recognising the sexuality of people in such institutions.

Access to needles may be appropriate and should be made available as in prisons. Condoms or needles should be supplied to people with intellectual or mental disabilities only under supervision and with counselling.

Closed institutions should not need to introduce routine testing of staff or inmates. If for special reasons testing is considered necessary, informed consent should be gained from the person before testing for HIV. Exceptions occur if testing is required by law, or when the person is a minor, physically unable to give consent, or for certain psychiatric patients. In the latter cases, consent of the legal guardian should be sought.

Under normal circumstances, there is no scientific reason to justify the segregation of any person known to be HIV-positive. Only where it is clear that an infected person is capable of a threat to others through action such as rape should segregation be employed.

The most important contribution that authorities and administrators can make is to educate their staff and those under their care, and to develop guidelines to treat HIV-positive people with sympathy and understanding rather than with fear and discrimination.

Possible policy components

- Provide HIV education and counselling programs for staff and for those in their care and their families designed to meet the needs of people in closed institutions.
- Provide access to condoms, but under supervision for people with intellectual or mental disabilities.
- Provide access to sterile needles, but under supervision for people with intellectual or mental disabilities.

- Amend government guidelines for closed institutions to acknowledge the implications of HIV transmission.

3.5.6 Adolescents

As the epidemic spreads into the general community, adolescents will become particularly vulnerable to infection. Adolescence is a time of experimentation with a range of behaviours, both social and sexual, and intense conformity to peer group norms. It is also a time when values are being established.

Programs should describe how HIV is transmitted and precisely how infection may be avoided. Emphasis on preventing transmission may depend on the setting of programs and the social or religious values which those settings represent. In many groups the values of sexual and drug using abstinence, marriage and sexual responsibility are positive adjuncts to HIV prevention education. However, education programs will need to stress that there is no alternative to the adoption of, and strict adherence to, protective practices in any sexual or drug using activity.

Preventive education for young people needs to be honest, explicit and comprehensive about the options which are available for preventing HIV infection. It also needs to be realistic in its assumptions about the attitudes, skills and behaviour of young people.

Reaching young people with messages about HIV prevention will require the development of programs for many media and social settings and need to include significant consultation with young people themselves. In previous educational campaigns this has proved to be an important strategy to ensure that the content and form of messages is appropriate.

Television, cinema and radio are particularly significant media for reaching young people. Advertising campaigns and the development of special programs to inform and motivate young people will be important components of the preventive education strategy. Editions of the ABC programs "Beat Box" on AIDS and "Blah Blah Blah" on condoms are good examples of responsible television programming. Youth magazines on fashion, music and sport could also have a key role.

In addition, youth cult personalities from the media and music scenes need to be encouraged to promote the cause of HIV prevention among their fans. They can act as powerful leaders and role models for preventive and compassionate messages.

Adolescents may reject messages which appear to come from authority figures and organisations; which appear to attack their lifestyle, beliefs and group norms; or which seem to have an exclusively adult emphasis or

origin. Nevertheless, the desire to be treated as an adult is also strong and an important factor in developing personally responsible behaviour.

Schools

The appropriate curriculum base in which to teach the prevention of sexually transmitted disease, including HIV infection, is in a health and human relationships education program, which deals with self-esteem, assertiveness, communication skills, relationships and sexuality.

Education programs need to be available to all school children and should:

provide factual information on HIV within the broader context of sexuality and relationships;

build upon and promote student self esteem and communication and decision making skills;

encourage students to examine critically and to understand their own and others' values; and

explore the total range of choices in preventing sexually transmitted diseases, including the right to say no.

Isolated presentations by guest speakers have limited value in helping students to develop and adopt the personal skills necessary to avoid infection with HIV. Education is an ongoing process and people who work with adolescents have the opportunity to provide role models to dispel fear and discrimination. Staff and parents need a factual understanding of HIV, so they can educate children. Strategies involving seminars and workshops, take home brochures, videos which prompt discussion in the classroom or at home, and guidelines set in advance by school boards, should be developed to encourage informed responses.

Education authorities have already accepted their responsibility to promote HIV awareness programs in all levels of schools. Although school systems vary considerably across Australia, common material can be established from which individual schools or departments could draw materials. A body made up of representatives of health and educational authorities could work together to develop this material further. Educational institutes could consider the merits of establishing committees responsible for developing programs, including representatives from parent groups, students, professional associations and unions.

Universities, colleges and other post secondary institutions

There are very large numbers of young people over the age of 16 in universities, technical or advanced education colleges or other educational institutions. They are more likely to be sexually active than those adolescents in school, but still unlikely to be involved in a permanent

formal relationship. They are more likely to encounter illicit drug use and to have some financial capacity and freedom to engage in drug use if they choose.

It is important to reach these young people with educational materials and programs about HIV transmission through their existing health and social services. The development of a guide about HIV for campus counsellors (Get Real, 1987) and programs, like the one developed by the Victorian AIDS Council and Melbourne University, have proved a useful beginning. Developing student health groups which can reach the mass of students with face to face and other programs is important.

Youth training centres

Many adolescents are confined in institutional settings, often because of drug use or drug related problems. Such settings play an important part in forming subcultural norms for young people who are or soon will be at risk of HIV infection, either through intravenous drug use or through sexual activity.

Preventive programs as part of the regular activities of such institutions will be most successful if designed and implemented by the target groups themselves, with assistance from others, and with access to relevant resources such as the comics developed by the "Streetwize" group.

The role of youth workers

Youth workers are in a particularly influential position to support HIV prevention strategies.

Although a group with little homogeneity in background, education or employment, they constitute a significant avenue of access to young people. They work on the streets, in crisis centres, from youth employment and training schemes, churches and other social service organisations, in drug and alcohol services and in many other settings.

Their roles and responsibilities are often very diverse and they are generally poorly resourced. Any attempt to impose additional responsibilities without additional resourcing is likely to be unsuccessful. Efforts should be made through existing youth worker associations and networks to encourage staff to develop and implement HIV prevention programs and to apply for funding where necessary.
Skills training for youth workers in HIV education and for counselling of young people about HIV risk behaviours is a priority for the prevention strategy.

Possible policy components

- Develop education and prevention programs for adolescents outside educational settings through

venues, youth workers, mass and other media, and youth cult personalities.

- Encourage school and other educational communities to set an example to children and adolescents in the appropriate responses to HIV-infected students.
- Educational institutions to develop material which is honest, explicit and comprehensive about the options which are available for preventing HIV infection.
- Youth training centres and correctional institutions to develop education and prevention programs which take into account the special needs of these adolescents.
- Support youth workers to help them educate and counsel young people about HIV transmission and risk behaviours.

3.5.7 Women

As the epidemic becomes more widespread, women are becoming concerned about their own risks of infection. In many ways, women are particularly vulnerable for their risk depends not only on their own actions but also on the behaviour of others. The modes of transmission are the same for women as for men and so their susceptibility must arise from the context in which transmission takes place.

There is a need to identify the range of sexual, social and economic factors which place women at risk of infection. One such factor is a lack of assertiveness in interpersonal or social relations. Education programs need to encourage women to develop skills in negotiating sexual and drug use situations and in communicating their decisions to others.

Young women are at particular risk, as their information on HIV and on sexuality is often inadequate and based on fear and myth. Young women may feel socially powerless and be subject to pressure both from their partners and their peer group to partake in unsafe activities. Education programs should include assertiveness training, particularly when addressing issues related to sexuality or to drug use.

Education must also encourage and make more appealing the use of safer sex options. Women's health centres and women's groups should be supported in their attempts to help women develop skills in negotiating and practising safer sex. Some women's groups have already begun this work and should continue to receive support.

Education directed to women who have, or whose partners have, a history of high risk behaviour must specifically address heterosexual transmission and the implications of HIV infection and pregnancy. Counselling regarding

the option of abortion, education about minimising transmission and associated issues should be readily available. Rape and sexual assault victims should be counselled about the possibility of HIV infection.

Women's organisations and individual women have an important role to play in preventing transmission. The underlying message about the means of containing the spread of the virus is that relationships and social interactions must be based on mutual concern and respect. This is a message that women can take out into the community as educators of children and adolescents and sources of information for others.

Women are the traditional carers in society. They will be increasingly involved in caring for HIV-infected people both in their homes and in institutional settings. These women can become important catalysts for attitudinal change in the general community and sources of accurate information on the modes of transmission.

Possible policy components

- Identify the sexual, social and economic factors which place women at risk of infection.
- Educate women on preventing transmission of HIV, and train them in the skills required to protect themselves.
- Mobilise women to help minimise transmission:
  - through their control of sexual and drug use situations;
  - through women's organisations;
  - as educators of children and adolescents;
  - as community models and sources of information.
- Provide access to counselling for women who have, or whose partners may have, a history of high risk behaviour, including counselling about perinatal transmission.

3.5.8 People who work as prostitutes

Governments need to develop flexible approaches to prostitution with the aim of minimising the spread of HIV among people who work as prostitutes and their clients.

Prostitutes usually work close to each other and have social networks which can be used to promote safer sexual practices. However, prostitutes who work outside these networks including women who work from their homes and alone will be more difficult to reach.

Most people who work as prostitutes are self-employed and so have an occupational interest in ensuring they remain in good health. They

recognise that condoms protect them from sexually transmitted disease and thus from time off work without income. However, the consistent use of condoms is difficult in the face of customer resistance. Education about safer sexual practices for prostitutes, including education about safer needle sharing, is already under way through the prostitutes' collectives operating in New South Wales, Victoria and Western Australia.

The rate of HIV infection amongst women who work as prostitutes in Australia is very low. In Sydney and Melbourne there are innovative programs run by the Australian Prostitutes Collective and the Victorian Prostitutes Collective. Levels of infection are higher among male prostitutes in Sydney and among drug using prostitutes generally. Outreach programs involving prostitutes collective volunteers are likely to be the most effective way of reaching women and men on beats. An educational video on sexually transmitted diseases and HIV has been prepared by the Australian Prostitutes Collective and should be widely distributed. An extensive program has begun to encourage brothel owners to establish and advertise safe houses where the use of condoms is mandatory.

In Queensland, Western Australia, Tasmania and South Australia it is illegal to work in a brothel or to solicit or loiter in a public place for the purpose of prostitution. In New South Wales, it is a criminal offence to be involved in brothel keeping or to solicit or participate in acts of prostitution in or near a dwelling, school, church or hospital.

In Victoria criminal penalties apply to street soliciting and loitering for the purposes of prostitution. However criminal penalties do not apply to a limited number of brothels with approved town planning permits.

Governments need to consider legislation, regulations and policing practices which prevent the establishment of prostitutes' collectives or work against attempts to minimise the spread of HIV among these people and their clients.

Possible policy components

- Assist in developing further an infrastructure to deliver HIV education and prevention programs.
- Educate prostitutes, clients and brothel owners on means of preventing transmission and on cofactors of transmission.
- Extend the program of safe houses.
- Review legislation, regulations and practices which may impede HIV education and prevention programs among prostitutes and their clients.

3.5.9 Blood transfusion and blood product recipients

Health authorities should continue measures to prevent HIV infection of people with haemophilia and blood transfusion recipients and the further transmission to their sexual partners and children.

Approximately 1800 people in Australia have haemophilia. Haemophilia is generally inherited, occurring in males but carried by females. However, 25 to 30 per cent of cases of haemophilia occur by mutation, and so can occur in families with no previous history of it [Ross 1988].

The most effective treatment for haemophilia is a blood product concentrate which contains the required clotting factors. This product is made up from small fractions of approximately 2000 blood donations. People with severe haemophilia are often exposed to 2000 blood donors more than once a week. Sixty to 70 per cent of people with severe haemophilia in Australia have been infected with HIV. Of the total haemophilia group who received any treatment at all in the six years from 1980 when the virus first appeared in Australia, to 1985 when the blood supply was secured, it is estimated 30 per cent now have HIV [Ross 1988].

The families and partners of people infected by these means need access to factual information, and support and advice on how to assist those who are HIV-infected.

The education message to children and adolescents with haemophilia must be frank and factual in addressing concerns they may have for when they become sexually active. Adults also need to have access to educational material which explains the modes of HIV transmission to their sexual partners. Adults who are considering having children must have access to appropriate counselling which can ensure they fully understand the implications.

To date much of this has been provided by the Haemophilia Foundation of Australia, which needs continuing support.

The Red Cross has conducted campaigns to encourage people who received blood transfusions or blood products between 1980 and May 1985 to come forward for testing. More active encouragement may be needed.

Continuing quality control in the production of blood products is undertaken by the Commonwealth Serum Laboratory. There is a need to monitor the spread of HIV 2 and HTLV 1 into the population so that decisions about the need to screen the blood supply for their presence can be made in a timely fashion.

Blood transfusion recipients who are HIV positive may often feel that current services and organisations are not adequate for their needs. The New South Wales Health Department has set up a Support Unit, TRAIDS,

specifically for transfusion recipients and their families. Other States may consider the merits of establishing or expanding similar support services.

Possible policy components

- Actively encourage counselling and testing for all people who received blood transfusions or blood products between 1980 and 1985.
- Ensure continued quality control in the screening of blood, blood products and organ donations.
- Continue educating and counselling people with haemophilia, infected blood transfusion recipients, their families and partners.
- Develop appropriate education and prevention programs for infected adolescents with haemophilia.
- Continue support for the HIV education and counselling services provided by the Haemophilia Foundation of Australia.
- Expand services to infected blood transfusion recipients and their partners and families.

3.6 HIV infection and the workplace

3.6.1 Policy development

Employers and unions both need to address the changing conditions brought about by HIV in policies on the prevention of transmission in the workplace.

As the number of HIV-infected people increases, there will be an increase in the number of HIV-related issues arising in the workplace. These will include the promotion of health and safety at work, personnel issues, including confidentiality and the prevention of discrimination, workplace educational programs to counter prejudice and fear from other employees or third parties such as customers, the changing nature of markets for certain goods and services, and new investment opportunities in HIV-related technology.

The trade union movement was one of the first groups to respond to the emerging epidemic in Australia. The plumbers and health sector unions in particular recognised the need to assess the risk of transmission to their members, to identify procedures to reduce or remove any occupational risk and to educate their members.

More recently, a number of employers have begun to formulate HIV-related policies or guidelines. The stimulus for this has often arisen from concern over the welfare of staff who travel or who are posted to areas of high HIV prevalence, from the need to respond to policies such as the demand for compulsory screening made by certain countries, from occupational safety concerns, or because they employ infected individuals.

Close links need to be established among employers, unions and health authorities as organisations develop HIV-related policies to enable the resolution of potential conflict through education and conciliation.

Trade union policy

In February 1988, the Australian Council of Trade Unions adopted the following policy on HIV:

> "The ACTU recognizes that HIV infection, which may lead to AIDS, is only one of a range of communicable diseases which workers may be exposed to. However, it is noted that there are only isolated circumstances in which people are exposed to HIV infection in an occupational setting eg health care industry.
>
> "Although less infectious than other more prevalent diseases such as Hepatitis B, HIV infection represents a serious threat to the

health of the Australian population. Therefore it is essential that the Trade Union Movement play a major role in HIV infection education and prevention.

"The ACTU believes that the most effective way of controlling the spread of the virus is through community education rather than legislation.

"The ACTU sees the following three elements as being essential to the unions response to HIV infection:

Implementation of occupational health and safety guidelines on infectious diseases in the workplace.

Provision of clear and accurate information on infectious diseases to all union members.

Protection of union members, particularly those perceived to be members of high risk groups, from discrimination in the workplace".

The ACTU Discrimination Policy states that discrimination on the basis of sexual orientation or physical impairment is unacceptable.

Union policies also include maintenance of confidentiality, avoidance of mass screening or general pre-employment screening, and provision by management of protective clothing as required for safe working practices.

Employer policy

Organisations will need to establish effective HIV information and education programs in the workplace and fair and effective HIV-related personnel policies and practices.

Explanation of policy should be undertaken by personnel from all levels of the organisation. Small group discussions and awareness raising meetings are an appropriate way to address the more difficult issues. Details of the policy must be readily available to all workers.

Liaison with staff associations and unions will greatly improve the chances of widespread worker acceptance of HIV-related policies. They should be formally consulted, and contribute to and endorse the policy.

In those occupational settings where there may be a potential risk of exposure to HIV, for example, in pathology or research laboratories, where workers may be exposed to blood, employers should provide specific, continuing education and training, as well as the necessary equipment to reinforce appropriate infection control procedures. They should also ensure that appropriate accident prevention and safety procedures are followed.

Possible policy components

- Develop HIV-related occupational health and safety policies.
- Establish close links between employers, unions and health authorities on HIV-related matters.

3.6.2 Occupational transmission

An occupational health and safety statement is commonly an industrially negotiated agreement. Alternatively, it simply forms part of company policy. Existing occupational health and safety statements should be updated to take account of HIV and, where they do not exist, they should be introduced.

Each workplace is different and it is important to take account of local conditions. However, there are common principles, laws and awards governing them.

The vast majority of workers are at no risk of acquiring HIV infection at work. Only workers directly exposed to blood or body fluids could be at risk. Direct exposure at work occurs through needlestick injuries, cuts with sharp instruments, exposure through mucous membranes, and contamination of open skin lesions with potentially infective body fluids.

Workers who may be at risk from these types of exposure are mainly employed in health care. Their particular needs are addressed under Objective 3. However, there are others who are at very small risk of accidental exposure to HIV in the course of their work. These include:

police, fire fighters and others giving first aid;
corrective services workers;
sewerage workers and plumbers;
workers in industries involving large amounts of cut or broken glass;
school, pre-school and child care staff; and
tattooists, barbers and others using invasive instruments.

No cases of transmission in workplaces in these industries have been recorded. Nevertheless, sensible precautions need to be developed and observed.

In New South Wales, Victoria, Queensland and Western Australia, there are regulations under public health legislation to cover commercial procedures involving skin penetration, such as tattooing, acupuncture and ear piercing. Tattooing has been suggested as the cause of infection with HIV in at least two cases in the United States [Doll 1988].

All practitioners of such procedures need to be made aware of the associated transmission risks and advised to sterilise their equipment or to use disposable equipment. Appropriate education and legislation to support this

should be considered by all States and Territories. Hepatitis B virus can be transmitted through the sharing and reuse of razors. Razors and toothbrushes should not be shared in any commercial situation.

Workers who were implementing routine and appropriate infection control procedures before the HIV epidemic do not need to change their work practices. However, HIV has highlighted the fact that many workers are not routinely implementing necessary precautions. All work facilities where workers may possibly come into contact with infectious materials should review their practices and introduce an infection control program.

Management or occupational health and safety committees should monitor adherence to these programs. For any failure to follow standard precautions, counselling, education and retraining should be provided.

Because the hepatitis B virus is also bloodborne, and is both hardier and more infectious than the HIV virus, recommendations, other than vaccination, based upon prevention of hepatitis B transmission will also prevent the transmission of HIV.

First Aid protocol

In many industries and occupations, accidents may occur which require first aid treatment or resuscitation. The risk of infection during first aid assistance is not significant if simple precautions are followed, so there are no grounds to withhold emergency assistance from anyone. If all recipients of first aid are treated as potentially infective and the standard precautionary procedures taken as far as practicable in all situations, there is no need to enquire about HIV infection status.

There is no reason to withhold resuscitation in the event of sudden collapse. Resuscitation bags or disposable devices for mouth-to-mouth cardiopulmonary resuscitation (CPR) should be made available and first aid personnel trained in their use. The decision to withhold direct mouth-to-mouth resuscitation from a person with HIV infection when a CPR device is not available is solely that of the individual providing assistance [AIDS Task Force 1988].

All first aid personnel should receive training in infection control procedures and any required equipment should be provided.

Possible policy components

- Institute appropriate occupational health and safety policies in all workplaces to minimise or eliminate any occupational risk of HIV transmission.
- Legislate to require minimum safety and sterilisation standards in commercial settings involving skin penetration.

3.6.3 Workplace education to minimise transmission

All employers have a responsibility to institute workplace education programs on the prevention of HIV transmission.

Government education and media campaigns have helped to raise the general level of awareness about HIV. Nevertheless, knowledge both within and between organisations. Employers can supplement this general community awareness with the specific message that there is no risk from working alongside an infected individual.

Employees with potential occupational exposure to blood or bodily fluids require information which concentrates on precautions to prevent infection. All relevant workers should receive this information.

Senior personnel, managers and supervisors should be prepared to deal with employee concerns about HIV in the workplace. Education programs should provide information on the medical aspects of HIV infection, advice on how to recognise and deal with HIV-related situations which might arise in their organisations, and should stress the importance of setting up and maintaining procedures which guarantee confidentiality about every aspect of employees' HIV-related status. Selective education efforts, or education only at the request of employees who desire it, may be unwise and could raise questions of discrimination.

Employers should take the initiative in counteracting fear and prejudice. One approach used overseas involves small group discussions to increase awareness about HIV and to allow questions to be raised. The company's formal position and the fact that HIV cannot be transmitted during normal workplace activities should be stated. Education programs assist employees with their concerns about HIV, set a tone of calm, responsible discussion and communication, and encourage people to deal with the facts and work through their fears.

Staff who express a personal concern about HIV infection can be referred to counselling services, to AIDS clinics or other resources, as requested.

Small business do not usually have personnel officers, training courses or written policies. An HIV-related incident in such workplaces could be disruptive simply because of small staff size. Policies and training courses need to be developed on a regional basis, possibly with the assistance of a community group, local council or relevant State or Territory government agency, or within trade associations or chambers of commerce.

Businesses will reap benefits from properly educating their staff on HIV. Clients, customers and the public can then be reassured that they will not be exposed to any hazard in their dealings with the organisation. Such risks are generally negligible but it is prudent to take account of public perceptions.

Possible policy component

- Employers in both the public and private sectors to develop education programs in advance of any HIV-related problem in the workplace.

3.6.4 Personnel policies and practices relating to minimising transmission

When formulating personnel policies on HIV infection, corporate managers have several interests to consider: retaining trained and experienced employees for as long as possible, maintaining relationships with customers and suppliers, maintaining a productive work environment, and encouraging cooperation and understanding among employees.

The currently low frequency of workplace HIV cases in Australia allows organisations the opportunity to develop an HIV workplace strategy acceptable to management and unions well in advance of having to deal with specific cases.

Other reasons for strategy formulation include the management of corporate health care costs and employee leave requirements, the need to comply with legal requirements and statutory regulations, and the promotion of a responsible and sympathetic corporate image.

Implementation of HIV-related personnel policies can put extra demands on all sections of an organisation. A commitment to the policy and its implementation is therefore required from all levels.

Overseas travel and postings

A number of important personnel policies and practices need to be considered by organisations which have staff who travel or are posted overseas, particularly in third world countries [Reid 1988]. These may include:

staff education on methods of transmission and their cultural setting, and appropriate methods to prevent transmission;

formulation of a policy on the recruitment of infected individuals;

formulation of policies on in-country medical treatment and medical evacuation, and investigation of the need for and cost of medical evacuation insurance;

examination of the adequacy of present workers compensation policies to cover work related or other infection overseas; and

development of policies on the employment and redeployment of infected staff, the education and counselling of all staff and the care and counselling of infected staff.

The WHO Global Programme on AIDS has developed a brochure titled AIDS Information for Travellers [1988] which outlines methods of transmission and the special requirements for travelling in infected areas. This brochure is available from the AIDS Unit of the Commonwealth Department of Community Services and Health.

Recruitment. Mandatory testing for recruitment is a contentious issue. Many of the medical arguments against the recruitment and overseas posting of infected individuals are inconclusive in terms of placing them at greater risk of progression of the disease. The wish of individuals to work in their chosen field should be respected.

Serious consideration will have to be given by the employer to the potential political issues inherent in such a posting. If an infected individual were discovered to have transmitted the virus to a host country national, there could be political repercussions.

Employers need to ensure that all staff understand their responsibilities and should require assurances of these individuals, as they do of all staff, that they will not behave in such a way as to jeopardise the work of the organisation whilst posted.

Testing policies in recipient countries. Organisations wishing to post staff to countries with mandatory testing policies for international travellers or foreign residents will need to consider their response.

Discussions could be held with the recipient government, outlining the HIV-related education and personnel policies of the organisation, possibly jointly with other organisations with field offices in the country.

If an organisation decides to test staff before such a posting, counselling and confidentiality procedures will have to be put in place first.

Briefings for staff going overseas. All organisations with staff going overseas, especially to third world countries, should have a policy of informing these staff on the means of preventing HIV transmission and of providing them with information about the disease. The effectiveness of the briefings and educational material, not only in increasing staff knowledge but also in bringing about the required behavioural changes, needs to be monitored.

Preventive measures in the field. A significant risk of transmission occurs in developing countries where injections for medical and therapeutic purposes are commonly used in both the traditional and modern health sectors and where sterilisation practices are inadequate.

Where injections are required in-country, staff should be advised to provide their own sterile needles and equipment whenever there is any doubt about the adequacy of sterilisation techniques. Staff travelling overseas, both male and female, should be advised to take supplies of condoms if there is any doubt about local availability or quality.

Many countries lack an integrated blood service. However, in almost all countries, there is at least one hospital or other facility where blood is tested for the presence of antibodies. These facilities could be identified in advance by employers or, where this is not possible, staff should be advised to identify them on arrival. This can be done through local hospitals or other health facilities. Arrangements should be put in place to ensure that where possible, in an emergency, the staff member is taken to a secure facility for treatment.

The main risk for persons travelling overseas is travel through rural areas. One of the most common causes of mortality and serious morbidity is trauma, usually associated with motor vehicle accidents, and often leading to exposure to locally donated blood.

Transfusion policies prohibiting the transfusion of local blood or establishing walking blood banks are interim. The WHO Global Programme on AIDS is assisting countries to secure their blood supplies in the hope that blood supplies will be safe globally by the 1990's.

Medical emergencies. Organisations will need to consider their policy in view of the problems involved with medical treatment in countries without secured blood supplies.

Legal liability of employers. It is conceivable that staff who become infected with the virus whilst overseas could claim damages against their employer, for example, on the grounds that they were inadequately briefed about modes of transmission of the virus, or on the grounds that they received contaminated blood whilst in their employ. The legal liability of employers needs to be clarified.

Workers compensation for field staff. The required coverage of workers compensation provisions for staff posted overseas needs to be decided. This is particularly important since legal action cannot usually be taken against an employer relating to an incident covered by compensation. Some organisations have decided that overseas service comprises the full time of the posting, not just during local office hours. Other organisations limit compensation to illnesses which can be shown to arise because of the nature of the work assignment. Drug and STD related illnesses may be specifically excluded from compensation. Employers and staff need to ensure that their current compensation policies cover the required field situations.

Fitness for work overseas. HIV infection should not of itself be sufficient grounds for the recall or discharge of staff who have been posted overseas.

While it is likely that infection will at some stage lead to serious or life-threatening illness, this has yet to be shown to be universally true.

Employee or customer conduct

There may be situations where fellow employees refuse to work with HIV-infected employees or demand their dismissal. It is important that management and unions both respond to the situation with information, education, counselling, small group sessions and other appropriate measures before considering corrective or disciplinary action. The ACTU and individual unions need to consider developing more explicit policies to support employers who hold out against pressure to redeploy or dismiss an infected person. The Trade Union Congress of the United Kingdom has endorsed such a stand.

Third parties, such as customers, may also exert pressure for the removal or dismissal of an HIV-infected worker. Employers should make reasonable attempts to persuade the third party that the infected person is not a health threat. A balance will need to be struck in such circumstances between the rights of the infected employee and the employer's need to protect his or her business interests.

Review and appeal procedures

There must also be an effective procedure for appeal or review of disciplinary action or dismissal to protect employees against discriminatory action. It would also protect employers from decisions of line managers who do not understand, or do not agree with, formal company policy.

Possible policy components

- Expand existing personnel policies and practices relating to serious illness to cover HIV-related issues.
- Establish HIV-specific personnel policies and practices in such areas as health and safety standards, overseas travel and postings, employer conduct and review and appeal procedures.

Objective 2:

To support, care for and to treat people infected with HIV

4.1 Educational measures for the support of infected people

People diagnosed as infected with HIV need education, support and counselling to assist them to assimilate the diagnosis and to learn to live with their health status. Education efforts so far have centred on preparing people to cope with anger and depression; counselling for adjustment to diagnosis; and, in the community, on preventing transmission and rebutting myths.

However, the fostering of compassion and positive action in the general community is a pressing objective and this, too, is achievable through education. The community needs reassurance that it can live with HIV-infected people in its midst, and education will achieve this by reducing people's fears, changing their attitudes and beliefs, and harnessing their energies and feelings into constructive behaviour.

Members of the gay community, hardest hit by the epidemic, have provided a good example by assisting each other to live with HIV and to care for those who are infected.

For many people, this community has been a source of hope for themselves and their families and a source of comfort for those who have been bereaved. It has enabled many infected individuals to continue to lead productive and fulfilling lives and to turn a positive test result from a sentence of death to a diagnosis of a condition which must be managed in the course of normal life.

4.1.1 Living with infection: education for infected individuals

Most infected people are cared for by their partners, families or friends. Education and other support services are needed to help this group to learn to live with the diagnosis, to develop appropriate caring skills and to assist them to deal with loss and death. In practice, this means the provision of counselling services, small discussion groups and peer support programs.

The programs need to be designed to inform, motivate and support infected individuals. They should address safer sex and sexual expression; the contexts in which disclosure is appropriate or necessary; child rearing and pregnancy; and safer drug use, where appropriate. General health issues concerning life style, diet, exercise, nutrition, stress management, treatment options, medications and symptom management should be included. Life planning, goal setting, financial management and practical problem solving are also needed.

Such education programs should be run in small groups by skilled workers based in the community. There is a consequent requirement to train paid and volunteer workers from the generalist health and welfare professions as well as specialists in HIV, sexuality and drug and alcohol fields to deliver the programs. To ensure the quality of education and counselling services, and the sensitivity of educators, accreditation procedures could be established.

Diagnosis for many individuals may be followed by periods of depression and hopelessness, feelings of isolation and rejection and suicidal episodes. Workers supporting HIV infected people through these negative periods will need to be especially skilled in the counselling and educational techniques needed to assist infected individuals to live productively with their health status.

In rural or non-metropolitan areas, access to programs may be difficult. Consideration needs to be given to providing funds to help isolated individuals travel to appropriate programs and support groups. These programs have the advantage of providing a forum for infected individuals to get together and to establish support networks. Such networks can be crucial in maintaining positive attitudes against fear or depression and community hostility or apathy, particularly for geographically isolated people.

Government and community bodies at all levels should be involved in the management and resourcing of such programs. Funding needs to be available from the Commonwealth, States and Territories on the basis of grants to approved educator organisations. The involvement of local government in developing and maintaining programs would be desirable.

The lead in establishing these programs would best come from the bodies already involved in HIV prevention and education, such as ANCA, AIDS Councils and Commonwealth and State departments dealing with community services and health. Monitoring and evaluation of programs is needed.

4.1.2 Living with infection: education for the wider community

Programs to educate the wider community about HIV must be based on an understanding of the community's perceptions of actual and perceived risks of transmission from contact with HIV-infected people, must address these perceptions and fears, and develop attitudes and responses which will obviate them.

Some of this can be achieved by a continuing national public education program through the mass media which dispels myths about HIV and reinforces the humanity of people affected by the epidemic. Personal stories such as "Suzi's Story" based on the testimony of people infected or members

of their families can be very powerful in generating understanding and compassion. Programs will need to be widely available and advertised.

Employers, trade unions and service providers such as local government councils and businesses offering domestic services and entertainment venues may need to initiate appropriate programs.

There are many non-government organisations in our community which provide essential and invaluable welfare services to the community, especially in caring for those who are seriously disadvantaged by poverty, drug or alcohol dependence, isolation or terminal illness. Some of the most extensive and hardworking of these are the pastoral care organisations associated with religious and other ethically based bodies. It has proved difficult for some of the paid and volunteer workers in these organisations to commit themselves to assisting people infected with or affected by HIV. Because of the early association of HIV with homosexuality and intravenous drug use, many people have felt a disturbing conflict between their moral or religious beliefs which condemn such behaviours, and their instincts and experiences which prompt them to care for people in trouble, whatever the cause.

It is important to defuse this conflict and to harness the energies and compassion of these organisations and their members. They provide millions of hours of tireless and caring work in areas where governments cannot or do not operate. Delay in initiating public education will deny many caring people a further opportunity to contribute to the community.

Political, social, religious and community leaders need to find a way through this tension and to initiate educational programs within their various organisations. Expertise and resources to assist this process could be made available from the Commonwealth, States and Territories, as well as other involved bodies.

Possible policy components

- Provide education programs including counselling, peer support programs and self-help groups for infected people to assist them to learn to live with infection.
- Establish professional standards for HIV educators through, for example, accreditation procedures for educators.
- Educate those in the wider community through programs to promote understanding and compassion towards those infected.

4.2 Strategies relating to the health of infected individuals

4.2.1 The provision of care

As with other illnesses, our society should accept the responsibility of providing appropriate health care and community services to all individuals infected with HIV.

In Australia, the community has access to a high standard of effective health care with a prime objective of improving the quality and enjoyment of life for the individual. The responsibility to develop policies and design programs relating to the health and welfare of individuals lies with Commonwealth, State and Territory governments, although service delivery programs may be administered by the public, private or voluntary sectors.

Existing community services could often be easily adapted and expanded to deal with some of the particular needs of HIV infected people. The Home and Community Care Program (HACC) is a principal source of funding for community care services other than acute illness. Many of its basic services could assist HIV-infected people. The main advantages of using existing services are their geographic spread, integrated care and efficiency. Where it is not possible to integrate services for HIV-infected people into existing services, separate services may need to be established.

As knowledge of HIV infection and HIV-related illnesses increases, questions relating to the limits of responsibility of the health care, community services and social service systems will arise. Decisions have already been made or exist de facto with respect to some other illnesses or conditions. For instance, not every person requiring dialysis has access to a kidney machine.

There are also competing demands on the allocation of scarce resources, both financial and human, between the treatment and the prevention of HIV infection. Policies need to be carefully and explicitly developed to ensure that there is a balanced resource allocation between prevention and treatment.

The epidemic in Australia has progressed to a stage where detailed long-term planning should begin. This will require a needs assessment to be undertaken for HIV program planning.

Possible policy components

- Use relevant existing health and community welfare services, with the establishment of special services where appropriate.
- Develop special services for HIV-infected people separate from existing services.

4.2.2 Counselling

Adequate numbers of trained counsellors are needed for HIV-infected people, their families, partners and other caregivers.

The systematic application of counselling to the people involved in the prevention and management of a disease is new. It is one of the more important strategies available to deal with HIV infection.

Counselling needs to be emphasised in all policy documents issued by health authorities, professional associations, professionals and others offering advice. Counselling has an economic function in encouraging the continued productivity and integration of HIV-infected people within the community. It can also minimise the cost of care and treatment by helping people to manage many of their psychological and physical health problems themselves.

Counselling at diagnosis

Counselling helps people through the crisis of diagnosis. A diagnosis of HIV infection is often perceived as a death sentence, one which may be associated with progressive dementia and will certainly be associated with social stigma, fear or hysteria. There is a need to provide psychological and social support to HIV-infected people throughout this period.

The process of adjustment

After diagnosis, there will be a necessary period of adjustment. For those people infected but without symptoms the goal of counselling is to allow the person to adjust to the diagnosis, to incorporate behaviour change to reduce the spread of the virus, and to cope with new information received about HIV, personally or through the media.

HIV-infected people with symptoms often have more complex needs and require the development of long-term therapeutic relationships with professional counsellors. Issues concerning living with illness and dying often predominate.

The role of counselling will be to strengthen individuals' control over their lives and help them to adapt to this new state and to the behavioural changes it will require. The benefit of emotional support volunteers trained and supervised by professional counsellors has been shown in the work of

the Ankali Project in Sydney. One third of the people with AIDS supported by the project die at home. This not only significantly reduces the demand on health care institutions but also improves the quality of the person's last days.

Some groups may have special counselling needs. This has been recognised by the provision of counselling services for HIV-infected people with haemophilia and for their families, and for people with transfusion related infection and their families. The particular requirements of women, particularly as mothers of infected children or as partners of infected men, still need recognition. Families with infected infants may need intensive counselling services.

Counselling for loss and bereavement

The person infected may lose access to education, employment, income, friends, family, partners, access to children or the possibility of having children. As the disease progresses, there may be physical and intellectual losses. There will be the impending loss of life. These losses cause grieving to the person infected and to those who are close.

Counsellors need to be skilled in the general aspects of loss and death and the specific aspects of HIV infection, including the social stigma, the time taken from diagnosis to death, the nature of the dying and the social setting of this disease.

Possible policy components

- Provide an adequate number of trained counsellors.
- Provide systematic counselling at time of diagnosis, for adjustment to diagnosis and for loss and bereavement.

4.2.3 Self-help groups

The concept of self-help and self-organisation for people affected by HIV is important in terms of their health and well being and their ability to control their lives.

Self-help groups have formed both in Australia and overseas to address the various needs of people infected by HIV. They are important in coping with social stigmatisation and discrimination.

People with HIV often view involvement in self-help groups, and in AIDS councils, as a good way to find out about the virus, get information on available services and to begin to understand what may happen to them.

Infected people can provide critical and educational input into identifying needs, designing, delivering and evaluating services. They will know if services are not operating properly or if particular needs are not being met.

Possible policy component

- Assist HIV-infected people to develop self-help organisations responsive to their particular needs.

4.2.4 Nutrition

Nutrition strategies need to be developed that will improve the health, quality of life and well-being of HIV-infected people.

It is known that poor nutrition can result in decreased immune function, but as yet there is little known about the relationship between nutrition and HIV infection. Maintenance of good nutrition from the earliest stages of infection would improve the health status of infected people and may delay the onset of HIV-related illnesses.

Nutrition education strategies must be tailored to the individual and the stage of their infection. In people with HIV-related illnesses, depending on the severity of the illness, energy expenditure may be higher than normal. Severe weight loss can impair immunological and vital organ function as well as adversely influence the development and outcome of infectious diseases. Appropriate nutritional support interventions need to be identified. Dietary supplements are used routinely with HIV patients in most outpatient clinics.

Nutrition education and support through dietary counselling of carers would benefit both infected people and caregivers. This should be a responsibility of the HIV case management team.

Progression of the disease is often accompanied by severe or chronic diarrhoea. This may be able to be managed through dietary modifications tailored to the individual's needs. The provision of nutritional support for terminally ill patients will be similar to that advocated in oncology and should aim to carry out the patient's wishes and to maintain hydration.

There is a need for more research on the nutritional status of HIV-infected individuals, to determine whether HIV-related illnesses are amenable to support or alleviation through nutrition and on the effect of the virus on gastrointestinal function. There is also a considerable need for research into appropriate nutrition education strategies.

Research into nutrition and HIV infection could lead to improvement in patient care, prognosis and life expectancy. Relevant expertise exists in the CSIRO, in other research centres and the food industry in Australia.

Possible policy component

- Develop programs to establish and monitor good nutritional status throughout HIV infection and illness.

4.2.5 Treatment of HIV infection and related illnesses

HIV-infected individuals and their health care providers now face increasingly complicated treatment options related to HIV infection.

Previously only people diagnosed with AIDS struggled with the decision about treatment. As more clinical trials are initiated, people at all points in the spectrum of HIV infection may face this decision. Some of the drug treatments which prolong life for patients with HIV infection have substantial incidences of serious and unpleasant side effects.

Health care providers can assist HIV-infected people to assess the advantages and disadvantages of trying experimental treatments and of entering clinical trials. Counsellors can help ensure that HIV-infected people make informed choices that fit their understanding of the disease and their view of how to be responsible for their own health.

Consent to treat

Treatment must be given only with the informed consent of the individual, or his or her legal guardians.

People may need to be assisted to make decisions about treatment in the terminally ill stage. In New South Wales it is possible for an individual to empower another person to make decisions about treatment in the event of his or her incapacity to do so; an ordinary power of attorney is not effective in this way.

Legislation in other jurisdictions could be considered to enable enduring powers of attorney allowing for medical decisions in the case of incapacity. This would simplify what is otherwise a complex legal area.

Chemotherapeutic treatment for HIV-related illnesses

The only anti-retroviral treatment approved for use in Australia in AZT, which is the most effective agent currently available. The Australian Drug Evaluation Committee recommended, in February 1988, the approval of the marketing, by Wellcome Australia Limited, of AZT for use in designated AIDS units in the treatment of adult patients with severe, symptomatic human immunodeficiency virus infection, provided that chemistry and quality control aspects and product information are cleared by the Department of Community Services and Health.

A clinical trial has been conducted with Isoprinosine. Trials are planned for two other drugs, AL721 and dextran sulphate. People with HIV infection need current advice on the efficacy and availability of the range of treatments directed against the virus itself.

Many HIV-related illnesses are preventable or treatable although treatment is often expensive and ongoing preventative therapy necessary. Much of the preventive treatment is being administered in outpatient or community based settings.

The most immediate problems for the Commonwealth, State and Territory governments concern the projected increase in numbers of patients requiring treatment for HIV infection and HIV-related illnesses and the high cost per patient treated.

At present, treatment of patients with HIV infection has largely been confined to those with serious HIV-related illnesses. However, if clinical trials now under way show that drug therapy commenced earlier in the infection, perhaps before any symptoms of illness, can delay the onset of illness and increase life expectancy, the demand for treatment could increase quickly and significantly.

Following the Commonwealth's provision of additional funds to State and Territory governments for treatment regimes, AZT will not be provided under the Pharmaceutical Benefits Scheme. Supply of AZT is restricted to approved public hospitals and clinics.

With the relatively small numbers of people in Australia affected by the HIV virus or AIDS, there are fewer clinical trials of potentially useful treatment drugs than in the United States or the United Kingdom.

When HIV-infected people wish to be treated with a drug which is available in another country, but not marketed in Australia, and not currently in clinical trial, the Department of Community Services and Health can approve importation of such drugs under the Individual Patient Usage scheme, provided certain conditions relating to demonstrated need, and adequate supervision, are met.

Consideration could be given to therapeutic drug development and production, considering that Australia has a world reputation in many of the scientific disciplines on which therapeutic drug development depends. Clinical research units in Australia are usually involved only in late stage clinical trials. The capacity exists for involvement in pre-clinical and early clinical development. Research into drug development is being undertaken jointly by the NHMRC Special Unit in AIDS Virology and the CSIRO, and also at Westmead Hospital and at the Bond University.

Australian production of drugs is important given the pricing arrangements of imported drugs. Australian production could ensure adequate quality control and lower cost to governments and infected individuals.

Consumer protection

A number of non-approved treatments are being promoted for HIV-infection and HIV-related illnessess which may have potentially serious toxic effects. There is a need to provide adequate information and protection to consumers on these treatments.

As with any illness for which there is no readily available and well recognised effective cure, there are many non-approved treatments being promoted by the manufacturers and used by people with HIV infection.

Consideration should be given to protecting these people from wasting their money on useless preparations and also from exposing themselves to potentially serious toxic effects. It has long been accepted that certain substances may not be advertised for the treatment of cancer and it may be appropriate to apply similar restrictions in respect of HIV infection.

Complementary and alternative treatments

There is an increasing demand by HIV-infected people for the provision of complementary therapies such as meditation, personal growth, stress management, assertiveness training, naturopathy, nutrition and acupuncture. Programs involving a holistic approach have been advocated and are currently being tested overseas.

Medical authorities have acknowledged the importance of various other factors in influencing progression of HIV infection in addition to chemotherapeutic treatment. In recognition of this, referral to other paramedical and alternative practitioners could be explored if individuals with HIV infection want access to complementary or alternative treatment programs.

Possible policy components

- Expand the range of treatments available in Australia, either through importation or local production.
- Provide current advice to infected people on the efficacy and availability of treatments.
- Continue availability of AZT only through approved public hospitals and clinics.
- Ban the advertising of ineffective substances as treatment for HIV infection or related illnesses.
- Provide access by people with HIV infection to complementary and alternative treatments which have no potentially serious toxic effects.

4.2.6 Needs of particular infected populations

Models of care for infected people have been built upon the health needs of homosexual men, because they are the overwhelming majority of all those infected. Other infected individuals may have different health needs because disease manifestation or progression may be different or because of other considerations. These needs should also be addressed.

Needle sharing drug users

There is a need to establish support groups and counselling services for HIV-infected needle sharing drug users.

Methadone programs are currently being expanded but policies need to be developed to assist HIV-infected drug users to gain immediate access to these programs and to ensure confidentiality is not breached. Infected drug users may also need support to maintain contact with treatment centres, with HIV-related health services and with community based support and care programs.

Procedures to assist and deal with infected drug users need to be evolved quickly.

Aboriginal and Islander people

Aboriginal and Islander communities will need help in understanding that the wish of an HIV-infected person to be cared for and to die in his or her own community need not place that community at risk of infection. Health workers, particularly Aboriginal health workers, need to be trained in community and home based care.

Importance is placed by Aboriginal people on being cared for in their communities and buried on their land. Whenever possible, they remain or return there as soon as any disease process is recognised as terminal.

Regulations for the transportation of infected bodies need to be widely disseminated to assist relatives of those who die elsewhere.

People in closed institutions

People in closed institutions requiring care and treatment must have access to services which are of the same high standard offered to all other members of the community. HIV-infected prisoners will need to be referred to treatment and support services on release.

If HIV infection results in segregation, authorities will need to address problems arising from housing infected people within small, confined and isolated areas. The effects on the infected individual may include depression, attempted suicide, violent behaviour, increased drug use and early progression of the disease. The effects of this situation may be lessened if these people have access to expert counselling.

In line with policies on other health problems, consideration could be given to early release of prisoners if facilities of the same standard available to the rest of the community cannot be provided.

Women

Infected women are often socially and geographically isolated. They tend to have few personal and social support systems and may also be single parents. Because of these factors, every effort should be made to assist infected women to form support and self-help groups among themselves, including assistance for travelling to meetings or to service centres.

HIV-infected women have particular concerns about children: being childless; having children and infecting them; leaving their children motherless; having their children taken from them; and exposing their children to social stigma. Pregnant infected women may need or request access to abortions. Infected single mothers may need additional assistance with child care and housekeeping.

People with haemophilia

It is the view of many people with haemophilia that their HIV infection is best dealt with in a framework of haemophilia care.

The HIV infection status of these people should not prejudice their access to treatment required for, or as a result of, haemophilia, as has been the case with some hospitals which have refused to perform surgical procedures on HIV positive people with haemophilia.

Counselling should be available for people with haemophilia to assist them when considering having children.

Possible policy components

- Establish support groups and counselling services for HIV-infected drug users and assistance to gain access to methadone and treatment programs.
- Train Aboriginal health care workers in community based care, and recognise the wish of Aboriginal and Islander people to be cared for in their communities and buried on their land.
- Refer HIV-infected prisoners to treatment and support services on release.
- Release HIV-infected prisoners early.
- Assist infected women to establish support and self-help groups.
- Provide access to abortion for pregnant HIV-infected women.
- Provide counselling for people with haemophilia who are considering having children.

- Provide access to medical services and procedures including surgery for infected people with haemophilia.
- Provide HIV treatment and related services to infected people with haemophilia within a haemophilia treatment program.

4.3 Infected individuals as part of the community

Equal participation in the life of the community should not be lost or impaired when a person, either child or adult, becomes infected with HIV.

All who contract an illness have the right to remain within the community without unjustified discrimination. Where medical or public health requirements entail the restriction of an infected person's rights, it must be demonstrably necessary and reviewable in the courts.

4.3.1 Infants and children with HIV infection

Authorities responsible for, or involved in, the care of children should develop appropriate policies and services for children who are HIV-infected, their families and other carers.

While the number of children in Australia who are HIV-infected is small, overseas experience suggests that the number may grow, primarily through increasing levels of HIV infection among female intravenous drug users, most of whom are sexually active heterosexuals and in their childbearing years.

The attendance of an HIV-infected child at a day care centre, pre-school, or school raises issues of confidentiality, care and safety for the child and his or her classmates. In addition, a climate of fear often surrounds infected children. It should not be left to individual institutions to develop guidelines. Many may be under-resourced, not sufficiently aware of the facts, or of the implications of issues such as confidentiality and safety. This could result in the introduction of inappropriate guidelines.

Government authorities which are either directly responsible for the administration of these institutions or in a position to influence their actions should develop guidelines with the object of enabling HIV-infected children to remain in school as long as their health permits. A uniform approach should be adopted between institutions and between States.

Some infected individuals or their parents or guardians will choose to inform principals or other members of the school community of their HIV status. Others will not. Where this information is disclosed, the infected individual, or the parent or guardian, should give specific consent to any further disclosure.

Unfortunately, children known to be HIV-infected are likely to suffer unwarranted discrimination, as may others in their families. They cannot be totally protected from this, but the arresting of community fears through consistent education aimed at parents, teachers and others who have contact with children, including people such as school bus drivers and sports team coaches, will serve to create a supportive climate.

To date the children in Australia who are HIV-infected have been cared for by their families or carers, who also need support. This support may take the form of emotional, spiritual, physical, financial assistance or just a few hours away from the home and the child. Governments and community organisations already provide such assistance and should be encouraged to extend help to these families.

Government authorities may need to deal with the problems of HIV-infected infants and children surrendered to institutions for adoption or fostering. These children may have been born HIV-infected or become so through child abuse. The benefits of developing policies to protect such children before having to deal with the problems are obvious.

Issues that may need to be considered in policy development include:

the technological problems associated with testing for HIV in infants; risk of infection from infected infant to carer, in the absence of simple precautions to prevent transmission;

the possibility of neurological impairment;

obtaining consent to HIV testing of children; and

consideration of prospective foster and adoptive parents being informed of the child's HIV status.

Some agencies have started to discuss these issues, for instance, the South Australian Children's Interests Bureau has released a discussion paper, and the Council of Social Welfare Ministers is looking at a number of issues affecting children and HIV.

Information and education should emphasise that children partaking in normal childhood activities are not a threat to the community.

Possible policy components

- Authorities responsible for schools, pre-schools and child care centres to provide guidelines for staff, parents and children to address HIV-related issues including fear of infection, confidentiality, care and safety.

- Provide education on the implications of HIV for people who work with infected children and for parents of other children.
- Government authorities responsible for adoption and fostering to recognise that policies may need to be reviewed to take into account the implications of HIV infection among infants and children.

4.3.2 Employment, education and training

HIV-infected people need equal access to employment, and to education and training which enables them to find employment and to stay employed for as long as possible.

Access to employment, education and training

It is becoming increasingly common for organisations to have in their employment HIV-infected individuals. Because of this, many employers have begun to formulate policies on HIV and employment.

A diagnosis of HIV infection, of an HIV-related illness or even of AIDS does not in itself indicate an inability to continue in productive employment. The effects of HIV infection and its progression vary widely among individuals, and developments in treatment may enable HIV-infected people to stay in the workforce for many years. During this time, the education and training investment in that person by society and employers will be generating production, and the person will be contributing to society.

Since HIV-infected employees need not constitute a risk for transmission of the virus, they should be allowed to continue working for as long as they are able to maintain acceptable levels of performance.

For most infected people, the opportunity to continue working even part-time is important both emotionally and financially. Without employment, infected individuals are a direct burden on social welfare and may suffer higher rates of progression to illness.

Governments may choose to legislate against discrimination in employment and training based on HIV status, or to promote codes of practice with employer groups and unions that aim to achieve the same ends. The advantage of law in this area is that it supports policies with sanctions; the disadvantage lies in its potential to become outdated and inflexible.

Testing for recruitment or selected occupations. Testing new recruits or existing staff for HIV where they are to receive extended and expensive training has been argued as a simple matter of balancing costs against the benefits the employer will receive in terms of years of proficient service. Any cost/benefit analysis of this sort must take into account advances in

treatment and the fact that testing a person is no guarantee that he or she will not contract HIV infection subsequently. The cost/benefit argument for excluding HIV positive people from some areas of employment or training could be extended to cover exclusion from employment and education generally.

Apprehensions have arisen about possible public health hazards that could result from neurological, cognitive or behavioural abnormalities occuring in otherwise symptomless HIV infected individuals. Such concerns have been linked to occupations with a potential for endangering public safety, for example civil aviation, operation of nuclear reactors or heavy industrial equipment.

A Consultation on the Neuropsychiatric Aspects of HIV Infection was convened in Geneva by the WHO Global Programme on AIDS and the Division of Mental Health in March 1988 to examine relevant, currently available data and formulate appropriate policy responses. Forty-eight experts from 17 countries attended this Consultation and concluded that there is no evidence that there are more clinically significant neuropsychiatric abnormalities in otherwise symptomless infected individuals than in uninfected people.

It concluded that there is no justification for HIV serological testing as a strategy for detecting functional impairment in symptomless people in any occupational group [WHO 1988]. Such impairment may exist for many reasons. Optimal public safety is ensured by directly testing functional capacity rather than HIV infection status.

Proposals for employment testing should be carefully examined to establish that they are justified by unique circumstances that cannot be addressed in any other way.

HIV-infected people in employment

Employers should be flexible in accommodating the needs of infected employees. No one arrangement is likely to be satisfactory for all HIV-infected individuals or for the term of any one person's employment.

Employers already have a number of existing workers' health policies which cover matters ranging from the amount of sick leave entitlement to concessions available to seriously ill employees.

In assessing the need for new policies and practices applicable to HIV infection, an employer may find it more convenient to amend existing policies rather than to establish separate policies specifically for HIV issues. This would recognise that people with HIV infection are entitled to the same rights and opportunities as employees with other serious or life-threatening illnesses.

Such an approach may assist in reducing coworkers' fears about the disease.

All HIV-related personnel issues need to be addressed within the framework of existing procedures, guidance, statutes, case law and regulation. A number of issues can be identified which may require policy development. Resolving a specific personnel problem could require an extensive knowledge of the clinical aspects of infection, the current interpretation of the relevant legislation and regulation, and of the organisation's own policies and objectives.

Confidentiality. A clear and comprehensive policy on confidentiality of information about the HIV infection status of individual employees, and on the protection of privacy, would guide staff who have responsibilities for personnel and related matters.

Because of the nature of HIV infection, infected employees may have serious concerns about the confidentiality and privacy of medical and other records relating to their condition. Employers do not have a right to know that an employee is HIV-infected. If this information is disclosed by the employee the confidence must be respected.

The consequences for individuals if their medical confidentiality is violated can be serious. Such a disclosure may also have damaging consequences for the industrial relations of the company concerned. Information about a person's infection status can be disclosed only with the specific consent of the individual. An employee may be able to seek redress in the courts from an employer who is negligent in maintaining confidence.

Where an organisation has a company doctor, the duty to maintain confidentiality is just as strict. Specific consent is required for company doctors to test for HIV. As for all medical staff, testing without specific consent may expose the doctor to the risk of legal action.

Even where testing is properly and ethically conducted, employers do not have the right to know either that an HIV test was performed or the results. Neither has the company doctor the right to know the result of an HIV test performed elsewhere. Any such disclosure can only occur with the specific consent of the employee.

Post recruitment testing. Organisations may be faced with the need to test current employees. This could happen with staff to be posted to certain countries requiring testing as a condition of entry. Testing could be voluntary or it could be imposed by the employer. In the latter case, such testing may constitute a serious breach of contract entitling employees to resign and claim enforced dismissal. It could also constitute an unlawful assault. Whether testing is done voluntarily or mandatorily, procedures for disclosing or withholding all information relating to the test need to be established.

Dismissal. HIV infection does not constitute a sufficient ground for dismissal. It remains unknown whether infection will lead in all cases to progression of the disease. Where a person works in a job which may involve a risk of infecting others, adequate infection control procedures should be enforced. Infected individuals should be able to continue in employment for as long as they are able to maintain acceptable levels of performance.

Leave conditions. HIV-infected individuals may request sick or annual leave or leave without pay for clinical management or treatment, or to recuperate from an HIV-related illness. In these situations, organisations can make a determination on the same basis as it would for other medical conditions.

Fitness for work. When progression of the disease occurs in an HIV-infected person, work performance may not suffer initially. Progression, whether mental or physical, is usually gradual with frequent stabilisation of the condition. If there are medical indications that the employee can no longer perform the duties of the position, consideration should be given to allowing the choice of redeployment within the organisation or retirement.

Measures to ensure the reasonable accommodation of HIV-infected staff could include changes to their work assignment through the use of job restructuring, redeployment or flexible working hours. As the illness progresses, an employee may choose to resign or may be determined medically unfit for work.

Employee conduct. Management may have to deal with performance or conduct problems of HIV-infected staff. Responses could include counselling, remedial or disciplinary action, but the response should take into account the possible effect of anxiety or depression on work behaviour.

Possible policy components

- Governments, employers and unions to formulate education, employment and training policies for HIV-infected persons which support and encourage a normal working life.
- Test for HIV to exclude infected individuals from employment, or from employment in certain occupations.
- Legislate or adopt codes of practice to provide redress in case of discrimination against HIV-infected people or their families and friends in employment, education and training.
- Private and public sector organisations to develop personnel policies and practices for employment of HIV-infected staff which cover confidentiality, testing, dismissal, leave conditions, fitness for work and employee conduct.

4.3.3 Income maintenance

Income maintenance mechanisms need the flexibility to encourage continuance in employment and to accommodate movement in and out of the workforce by HIV-infected people according to the state of their health. Their interests and those of the community are best served by their leading normal productive lives.

There is a safety net available to meet the income security needs of people unable to obtain or retain employment. Income maintenance strategies designed to allow HIV-infected people to remain in employment for as long as possible, or to re-enter the workforce after a period of illness, would assist the individual and add to the nation's productivity.

However, the existing income maintenance mechanisms may lack the flexibility to allow movement in and out of the workforce. Problems may also be encountered by HIV-infected individuals and others owing to delays in the granting of benefits and the added costs of health needs generated by specific illnesses.

People with HIV infection or HIV-related illnesses are eligible for the same income maintenance assistance as the general population. These payments include unemployment benefit, sickness benefit, invalid pension and carer's pension.

The Department of Social Security makes a distinction between people who have HIV-related illness and those who fulfil the clinical definition of AIDS. Current practice provides those who have HIV-related illnesses other than AIDS access with sickness benefits, while those diagnosed with AIDS automatically receive an invalid pension. This distinction may not reflect the individual's health status since some HIV-related illnesses are as incapacitating as AIDS. It may need review, perhaps automatically transferring long-term recipients of Sickness Benefit to the Invalid Pension, with determination of the person's medical condition on a regular basis.

A major difference between invalid pension and unemployment and sickness benefits concerns access to the Pensioner Health Benefit (PHB) card and associated benefits. The PHB card is provided to all invalid pensioners and their dependants provided they meet the relevant income test. The major benefits of the card are free medical and pharmaceutical services together with a variety of State and local government concessions, including access to a Pension Transport Card.

Recipients of unemployment and sickness benefit do not have access to the PHB card. Instead they use the Health Care Card and the Health Benefits Card respectively. Neither the Health Care Card nor the Health Benefits Card provide access to the complete range of State and local government concessions available to PHB cardholders. Benefits vary greatly between and within States. Where substantial benefits are provided to Health Care and

Health Benefit cardholders there may be little difference between the three cards.

There are two other social security allowances which may be relevant to some cases. A mobility allowance of $11 per week is payable to handicapped people aged 16 or over, in gainful employment or undertaking vocational training, who cannot use public transport without substantial assistance. A remote area allowance of $14 per week (individual) or $19 per week (married couple) is a tax free allowance payable to pensioners/beneficiaries resident in defined remote areas.

The income maintenance system also provides widow's pensions to spouses of people who have died from an HIV-related illness who qualify under the relevant income and assets test.

The Social Security Review headed by Professor Bettina Cass has published a discussion paper on income maintenance payments for sick and disabled people. That paper canvasses the possibility of introducing a disability allowance as a separate payment in addition to the normal invalid pension or other social security payment.

This review raises many issues relevant to people with HIV infection such as whether or not they have special needs for additional income support or other cash payments, and whether assistance is best delivered in the form of cash payments or additional services. It may be more appropriate to change the range of benefits or services provided through existing Medicare, PHB and Health Benefit Card arrangements, the Health and Community Care Program (HACC) and the public hospital system.

Rather than introducing special payments or services, an income maintenance policy could focus on providing assistance to people with HIV infection within the scope of existing programs and arrangements. Any proposal for specific assistance to people with HIV infection would need to identify and to address specifically the additional costs incurred.

This approach may mean changes to existing policies to ensure access to needed health and other services, both for those eligible and not eligible for the PHB card. In particular, consideration could be given to previous HIV-infected Health Care, Health Benefit or PHB card holders to retain eligibility to these entitlements for one year after workforce re-entry. This is current policy for Invalid Pensioners only. In general, there is a need to examine a range of possible incentives for workforce re-entry.

A review of the additional costs incurred by people with HIV infection is desirable. Significant costs are associated with the home care of infected people [Haemophilia Foundation of Australia 1987]. Other costs may vary because of the wide variation in clinical symptoms of HIV infection and the personal circumstances of infected individuals.

Those who work in the area of income maintenance need to ensure that in the delivery of services to HIV-infected people, individuals are treated without prejudice and confidentiality strictly maintained. They need to be made aware of policy regarding HIV-related claims so they are able to process them promptly. Record keeping systems should be scrutinised to ensure that procedures guarantee confidentality.

Possible policy components

- Review current income maintenance and related health card benefits to determine whether adjustments are appropriate because of HIV-related illness.
- Introduce a flexible allowance or benefit arrangement to enable, in combination with existing benefits, infected people to remain in the workforce or return after periods of invalidity.
- Train staff in the area of income maintenance to ensure HIV-infected people are treated without prejudice and that procedures to ensure confidentiality are instituted and strictly implemented.

4.3.4 Access to housing

Public and private sector housing administrators need to consider their policies toward people whose circumstances change, including the particular difficulties of HIV-infected people and their families.

A combined public and private sector approach

Governments and the home finance industry should consider assistance to lessen some of the fears and stresses felt by HIV-infected people and their families. Such assistance should be in the broad context of public and private sector treatment of any home owner who contracts a serious illness, but two additional factors should be noted. First, the nature of HIV infection may allow for extended periods of wellness during which a return to the workforce is possible and desirable, and secondly, stress, by depressing the immune response, could initiate or hasten progression of the infection.

A reasonable outcome for the borrower and the financial institution need not involve public sector intervention. However, there may be scope for the public sector to provide a safety net which would encourage greater flexibility in the private sector. Commonwealth-State cooperation would facilitate changing existing policies to meet the special problems faced by people with HIV infection. The basic principle should be to maintain people with HIV infection in their existing or appropriate accommodation for as long as is feasible and desirable.

Public rental housing

HIV-infected people who are renting in the private rental market may experience severe housing problems because of discrimination, loss of income, or because of health care costs. Public rental housing could be made available in the same way as for other disadvantaged people, wherever possible near their treatment and day care centres.

Home ownership assistance

There are existing State housing assistance programs which could assist people with HIV infection, including the mortgage relief scheme and the home purchase assistance program.

Existing mortgage relief schemes deal with short-term problems faced by house purchasers in meeting their mortgage commitments. HIV-infected people may already be eligible to use this program to cover their mortgage commitments during periods of temporary withdrawal from the workforce owing to illness. The mortgage relief schemes do not deal with a permanent reduction in income.

Under the home purchase assistance program, longer-term assistance could be provided to HIV-infected people and their dependents to allow them to stay in their homes.

It may also be possible in some cases for housing authorities to buy the homes of HIV-infected people. Public spot purchases would permit continued occupancy by people with HIV infection and their families and avoid the forced sale of houses on the private market.

Modifications to existing programs, including the extension of mortgage relief schemes on a longer-term basis to people with HIV infection, could be considered by the States. New arrangements involving the public sector could be developed to assist people in need of financial assistance by using part of their existing home equity to meet necessary expenses, including the payment of debt servicing charges on houses. Funds so advanced to an individual would subsequently be reclaimed from the estate of the deceased person.

Home ownership in the private sector

Access by HIV-infected people to private sector housing finance such as bank and building society loans is currently determined on normal commercial criteria. A house purchaser with HIV infection may have an uncertain future income but that should not necessarily preclude completion of the purchase of the house.

Financial institutions deal with clients facing difficulties in meeting mortgage repayments in a variety of ways. In general, a sympathetic but firm approach is adopted towards people facing genuine difficulties, provided they discuss their situation with the lending institution. Temporary

problems are dealt with by loan or repayment restructuring, although the proper concern of financial institutions is to protect their loans.

Mortgage insurers generally let financial institutions determine the procedures for resolution of problem loans. Financial institutions are influenced by the longer-term prospects of the borrower in coming to a decision as to how to resolve problems. Financial institutions prefer to avoid repossessions and sales. Where completion of a purchase is impossible, a forced sale can still be avoided; interest or mortgage repayments can be deferred until the property is sold as a deceased estate.

Possible policy components

- Involve both the public and private sectors in determining mechanisms by which HIV-infected people can remain in their own accommodation for as long as feasible and desirable.
- Provide public rental housing, in the same way as for other disadvantaged people, and wherever possible near treatment and day care centres.
- Public housing authorities to spot purchase homes of HIV-infected people to allow them continued occupancy.
- Use existing State housing assistance programs to assist HIV-infected people to stay in their own homes.
- Modify existing programs to allow for special needs of HIV-infected people.

4.3.5 Life insurance

Since HIV infection shortens life expectancy, it has a direct impact on life insurance. The issues confronting insurers and proposers include ensuring that unfair discrimination is avoided, that confidentiality is maintained, claims are promptly and correctly settled, and the interests of proposers, insurers, and other policy holders are protected.

The insurance business is based on differentiating between different classes of risk. Underwriters determine whether insurance cover should be provided, and the premium which should be charged. Life insurers argue that it is legitimate to attempt to identify and exclude people at risk of contracting HIV in order to ensure that other policy holders do not have to pay unacceptably high premiums, and to protect insurance funds from financial difficulties.

Relying on market forces to shape the industry's response to AIDS was rejected by the industry and by the National Advisory Committee on AIDS in 1987 as offering insufficient protection either to the industry or to HIV-infected people. Following recommendations of a NACAIDS working group on insurance in 1987 that a code of practice be drawn up with the industry, a

Commonwealth/industry working group drafted a code which was endorsed in April 1988 by the Minister for Community Services and Health and the Life Insurance Federation of Australia.

The code of practice does not permit insurers to discriminate against people solely on their known or suspected sexual preference, nor on the grounds that they have previously had a test for HIV infection. It provides guidance to insurers on the form of declaration for proposers seeking cover below the threshhold, on confidentiality requirements, and on how proposers should be counselled prior to undertaking a test. It allows for testing to be done, with informed consent, by the applicant's own doctor or as arranged by the company.

The code of practice is voluntary and at this stage is accepted only by members of the Life Insurance Federation of Australia (LIFA). LIFA covers all major life insurers other than State government insurance offices. State government offices and members of the Insurance Council of Australia have been asked to endorse the code.

There is no formal mechanism contained within Commonwealth insurance legislation to handle complaints against insurers. Complaints are handled by various bodies in an ad hoc way, and resolved by negotiation between parties. Whether this arrangement is likely to work satisfactorily for increasing numbers of HIV-related claims should be considered.

If monitoring the industry reveals a significant level of departure from the Code of Practice, remedies may need to be developed in consultation with industry groups. These could include legislation or an insurance complaints unit.

Insurance companies in Australia require all people seeking life insurance coverage exceeding a particular threshold to undergo HIV testing. Currently the threshold is around $400 000 for life insurance and around $5000 per month coverage for disability insurance. However, LIFA is concerned that the current limit is too high and has proposed reducing it. Proposers who are HIV-positive are not accepted; nor are proposers who are intravenous drug users, or who engage in male to male anal sexual activity in a way that involves a high risk of HIV transmission.

Claims by people who have contracted HIV infection after taking out life insurance should be protected by normal industry practice. However, concerns have been expressed that some companies may be refusing or delaying payment on HIV-related deaths even where there is no suggestion of dishonesty on the part of the insured. It is industry practice to examine more closely claims resulting from premature death but there should be no lengthy delays in paying HIV-related claims.

Insurers are protected from non-disclosure of HIV infection in the model declaration form in the Code of Practice, but there will be some cases where

it will be impossible to state with certainty that a policyholder was unaware of infection at the time the policy was written.

If significant numbers of such doubtful cases emerge over the next few years, it is likely that insurers will lower the threshold for mandatory testing to a level that takes in all new applications for life or disability insurance. In addition, life insurance companies which offer group insurance through employers are currently examining whether they can continue to do so without medical information from employees.

The normal practice is for insurers to bear the cost of testing. Full costs incurred by approved government laboratories should be charged. Ultimately, these costs may be added to insurance premiums. The number of positive tests is likely to be small, taking similar large scale testing of blood donors as a guide.

Government and the insurance industry need to address a further point. People with existing insurance policies who subsequently develop HIV-related illnesses may be unable to continue paying premiums until their death owing to loss of income. A mechanism to allow the continuation of premiums is required. The government could establish a rolling pool of funds charging commercial rates and recovering from estates, or insurance companies could fund the premiums on commercial terms, then deduct the amount owing from the policy settlement.

Possible policy components

- Rely on market forces to shape the industry's response.
- Government and the entire life insurance industry to agree on a voluntary code of practice to deal with HIV-related issues.
- Extend existing insurance legislation to eliminate unfair or irrational discrimination and to address issues such as confidentiality and testing.
- Establish an insurance complaints unit.
- Establish mechanisms to assist HIV-infected people to continue premium payments after loss of income.

4.3.6 Health insurance

Unlike the life insurance industry, where proposers for policies are risk rated on health and other factors and may be rejected as bad risks, the Australian health insurance industry operates under a community rating principle. This principle requires health insurers to accept all applicants.

The purpose of community rating is to ensure that all contributors are treated equally with respect to contribution rates and entitlement to benefit. Community rating has been supported for many years by successive

governments and the health insurance industry. Change does not appear warranted by the present or predicted levels of HIV infection.

The arrangements for pre-existing ailments provide that where a new contributor or his or her dependants have signs or symptoms of illness or a condition such as pregnancy at the time of joining a health fund table, he or she is not eligible to claim subsequent hospitalisation costs related directly to that illness or condition within twelve months of joining. After twelve months, all claims must be paid. A person who is HIV-positive but showing no signs of illness is not currently regarded as having an illness or condition that would prevent subsequent hospitalisation claims being paid.

Some private health insurers have expressed concerns that a significant percentage of HIV-positive people joining health funds under the current arrangements will, within a few years, make increasingly frequent claims for periods of hospitalisation. The private insurers argue that HIV positivity has such a high likelihood of progression to illness that it must be considered as a pre-existing condition requiring an extension of the current eligibility arrangements.

Almost all people with HIV-related illnesses are treated under Medicare in the specialist AIDS units located in public hospitals. AZT is available only through these institutions. The Commonwealth government is providing an additional $15m in 1988/89 specifically to assist the States in providing care and treatment to AIDS patients.

Possible policy components

- Maintain health insurance arrangements for HIV-related conditions as for any patient or illness.
- Maintain the current arrangements applying to pre-existing ailments for health insurance of HIV-positive people.

4.3.7 Superannuation

A consistent and fair approach to superannuation will protect the HIV-infected individual's employment prospects and benefit entitlement as well as the viability of the superannuation industry.

Superannuation coverage raises issues similar to those raised by life insurance. A code of practice for superannuation needs to be discussed by governments and industry representatives with a view to adopting a consistent and fair approach.

Many superannuation policies offer the payment of benefits for death and/or disability. These are called benefits-promised superannuation schemes. The other major type is the accumulation scheme which does not offer special benefits on death or disability. The benefits in these cases are

confined to the accumulated savings in the member's account in the scheme. Many union schemes are the accumulation type, though some also offer death benefits.

Most Australian superannuation schemes are not sufficiently large to self-insure the risk of death of fund members so group life insurance is purchased to cover potential superannuation liabilities. Most group life coverage forming part of superannuation coverage does not involve separate proposals on the individual insured. As a rule, group policies operate by identifying only those people wishing higher than usual coverage and requiring individual assessment.

Many superannuation schemes do not make medical examination compulsory for membership. This allows the possibility of people who know they are HIV-infected joining superannuation funds offering group death and disability coverage to all employees.

Superannuation fund managers should examine ways of providing superannuation coverage which retains protection for the fund but makes specific provision for HIV-infected employees.

The Commonwealth, as an employer, offers modified superannuation coverage to people with HIV infection. This coverage is equivalent to an accummulation scheme until the employee has been employed for twenty years; beyond that full normal superannuation, including death and disability coverage, becomes available.

Under the Commonwealth scheme, the medical test includes a question about HIV status but there is no testing for HIV antibodies. Permanent employment is not denied to anyone with HIV on those grounds. Some people with AIDS may be judged not able to work on medical grounds.

It is reasonable to expect some differentiation in benefits offered to people known to have HIV infection at the time of joining a superannuation scheme giving death and disability benefits. However, employment prospects should not be reduced because of ineligibility for such schemes. Superannuation benefits should still be offered to all employees even though, as with the Commonwealth, this may require a modified scheme for people known to have HIV infection or other serious health conditions.

There should be a requirement, either in the proposed code of practice or in legislation, to ensure that the benefits of such schemes were comparable with the normal superannuation coverage. This could easily be assessed in terms of annual actuarial cost of the scheme to the employer.

The obligation should be on employers to offer comparable superannuation benefits to all employees. The Commonwealth's practice provides a model.

Possible policy components

- Develop a code of practice for superannuation funds similar to that adopted by the insurance industry.
- Provide benefits to employees who are HIV-infected.

4.3.8 Compensation

Compensation to HIV-infected people who have acquired HIV through blood transfusion, through use of blood products or through other medical interventions, either directly or as a partner or child has been proposed by bodies such as the Haemophilia Foundation of Australia. There is a need to determine whether compensation should be paid, and if so, by whom and to whom.

People who are adversely affected by medical intervention of any kind have a common law right to seek compensation, but the plaintiff must prove negligence by the defendant, court delays can be extensive, and outcomes are very uncertain.

There have been no successful claims against Australian Blood Transfusion Services for transmission of HIV through infected blood or blood products. In all States and Territories, there are arrangements, including legislation in all States except Queensland, to protect the Blood Transfusion Services from civil liability suits relating to HIV transmission.

Removal of people's rights to civil action raises the issue of compensation, but does not provide an incontrovertible argument in its favour. Indeed, it can be argued that without the free gift from society of blood and blood products, many people would die or be seriously financially handicapped, and it is therefore inappropriate to claim compensation for illness or death which might arise unforeseeably from those gifts.

Many treatments contain an element of risk, which people accept as preferable to the illness itself. Blood and blood products can cause a number of illnesses, but are relatively very safe. Even if there were no test kit available today for detecting HIV antibodies, there would still be situations where people might be prepared to run the risk of HIV infection in order to survive a critical operation or to recover from serious injuries.

Governments could consider a no-fault compensation scheme which covers all medically acquired illness, including HIV infection. If the common law right to sue for damages in medical cases were removed, there would be considerable savings in medical litigation insurance, benefits would be clearly specified for the circumstances rather than varying between court judgments, the difficulty of proving negligence would be made irrelevant, and court delays eliminated.

On the other hand, the establishment of a no-fault compensation scheme for medically acquired illness is not without problems. Defining the difference between medically acquired illness and other illness would not always be clear, particularly in psychiatric cases. Consideration would need to be given to cases arising from non-medical interventions. The scheme would need to be funded by the medical profession, by governments, or by levy. Opposition could be expected to the removal of the common law right to sue for damages. The setting of benefits appropriate to each possible type of compensation claim would be complex, and could lead to a substantial bureaucracy to deal with cases. Distinctions between medically acquired illnesses attracting a benefit and the majority of illnesses which did not might lead to the same difficulties that currently beset workers' compensation, and to a lesser extent no-fault traffic accident schemes.

The British Government recently announced the establishment of a 10 million pound trust fund to be administered by the Haemophilia Society of Great Britain. A claim for a similar trust fund has been made by the Haemophilia Foundation of Australia. They argue that the administrative difficulties which may emerge in a broad compensation scheme would not be present in one applying to infected people with haemophilia: they are clearly identified and there are a limited number of people who would be eligible. They also argue that their cause of infection was through treatment intended to keep them healthy, which creates a moral obligation on the community to provide compensation.

A limited eligibility scheme of this kind, or one covering all those who directly acquired HIV infection through transfusion, blood products, artificial insemination, or organ transplant or their infected partner or children, raises questions of equity. Anyone with another severe medically acquired illness or disability could claim that they should receive similar compensation. Anyone who has suffered loss of income, employment, marriage or parenthood prospects through illness might reasonably claim that the most important factor for deciding who receives government compensation is not the cause of the illness, but the need of the claimant. Those who acquired HIV infection through sexual activity might ask why they are being excluded from benefits when no other government benefits program makes such a distinction. And people with a disability might ask why a compensation scheme should be created for a group who became ill when receiving treatment provided in good faith at no cost by the government, but not for people whose disability is congenital or the result of severe illness.

The fundamental issue is whether the community is providing a sufficiently broad safety net of benefits to people who are ill and their families. In Australia, the universal coverage of Medicare for medical and hospital needs and the Social Security benefits schemes relating to income maintenance remove much of the argument for compensation that might apply in countries where there is little or no government support and where blood and blood products must be purchased. If there are treatment or other

direct costs not adequately covered by existing schemes, it is the responsibility of government to examine the shortfalls and to decide how they may be addressed.

Compensation for HIV infection, however it has been acquired, is not an issue on which there will be easy consensus.

Possible policy components

- Medically acquired HIV infection to be regarded as being no different from other medically acquired and sometimes fatal conditions which are not subject to any government compensation scheme, on the grounds that there are extensive income maintenance and other benefits provided by governments for all eligible persons, without regard to the cause of invalidity or loss of employment.
- Governments to pay compensation to infected individuals or their families to cover consequences such as loss of income, denial of insurance, extra treatment and home care costs and loss of quality of life.
- Pay compensation only to those who acquired HIV infection solely through medical intervention.
- Pay compensation to all who acquired HIV infection before modes of transmission were identified and publicly known.
- Establish a special assistance fund to enable grants to be made on a case by case basis.

4.4 Health and community services planning

4.4.1 Case management

Case management procedures need to take into account the complex ways in which HIV infection may manifest itself over a number of years. They should provide for maximum coordination and cooperation of all individuals and organisations involved in the treatment, care and support of an HIV-infected person.

Present case management procedures have evolved for the management of patients in hospital care. They have led to serious discontinuities and omissions in the care of HIV-infected people.

Procedures for HIV-related illnesses, including impairment of the central nervous system, need to take into account the treatment of HIV-related illnesses, the consistent but irregular movement of infected people between clinical and non-clinical situations, the need for extensive counselling and other support, the desire of many patients to make their own decisions about treatment and places of care, the duration of the illness and the important role played by non-professional carers including family, friends and partners. These procedures will also need to accommodate special factors arising from, for example, intravenous drug use, haemophilia or perinatal transmission as well as the impact of non-medical factors on disease progression.

The concept of a continuum of care has been promoted as the ideal model; it implies a network of services working in a complementary manner to offer infected individuals a consistently good level of care, information, education and support.

The case management team would be responsible for advising and assisting the patient and for ensuring the services provided are complementary. The team coordinator would need to have knowledge about the range of situations or services likely to be required by an infected person. Other medical and non-medical personnel work with the patient as equal members of the case management team. Supportive work practices would need to be adopted for these teams.

Effective case management, which begins with the initial contact with an infected person and continues on until after death, minimises the demands made on more expensive forms of health services. Large savings in hospital costs, along with the improvement of the person's quality of life, can be achieved by such a continuum of care.

Possible policy component

- Develop case management procedures to ensure a continuum of care with maximum coordination and cooperation of all involved in the care and treatment of HIV-infected people.

4.4.2 Provision of counselling services

Planning is needed to ensure that comprehensive and consistent counselling services will be available to all HIV- infected people and to their carers, families and close friends. This will require the coordination of existing government and non-government services both at the service level and at the level of the individual. Inadequacies in the present services will need to be identified and overcome, and appropriate training made available.

Health authorities are responsible for the adequate recognition and resourcing of counselling as an essential health service, for the provision of multilingual services, for the rapid dissemination of new information and for macro-level planning, organisation and coordination of services.

It is no longer feasible, at least in New South Wales, to rely solely on HIV-specialised counsellors for the provision of all HIV-related counselling. All counsellors will need to be offered training in the issues surrounding HIV infection. The existing pool of expertise in HIV counselling is an important resource for this purpose.

Training should take account of the impact of HIV infection as a complex interaction of medical, social, psychological and moral problems and issues. It should deal with the adjustments required for living with HIV infection and be sensitive to special factors such as sexual orientation, intravenous drug use, age and a wish to have children.

The National AIDS Counsellors' Association has recommended the appointment of an AIDS counselling coordinator in each State and Territory. Such a person could be responsible for establishing standards of HIV counselling, particularly pre- and post-test counselling and training programs for existing counsellors; monitoring services providing HIV testing and information in order to ensure that HIV counselling is adequate; identifying groups with specific needs, such as Aboriginal, Islander and non-English speaking communities; and developing culturally relevant programs using health professionals from the communities involved.

Possible policy components

- Plan to ensure that adequate numbers of trained counsellors are available for HIV-infected people, health care workers and other caregivers.

- Health departments to consider appointing HIV counselling coordinators.
- Provide training in counselling issues relating to HIV for:
- all counsellors who wish to work in this field;
- HIV-dedicated counsellors.

4.4.3 Planning for the neurological aspects of HIV infection

The possibility of central nervous system impairment in HIV- infected people is only beginning to be understood and service provision in this area is in the early stages.

Those working in primary care provision for people affected by HIV need to be educated on the psychological and neuropsychiatric aspects of infection, trained in home and institutional care of people with HIV-related intellectual impairment, and acquainted with and aware of the sources of assistance available, and the mechanisms of referral. Educational resources must also be developed to support the systems of care. Administrative recognition of the need for support and relief for care givers working with this distressing condition is needed.

The stigma associated with mental impairment will need to be confronted. Not only is there distress engendered by the stigma of the disease itself, the irrational fears it produces in others, including many health professionals, and the rejection that many of those at risk or infected face from society, there is further stigma that arises with the loss of intellectual functions. It is critical that understanding and attitude change are incorporated into service development and provision to lessen the burden.

Community based and inpatient services for people with AIDS dementia complex will need to be developed as more becomes known about the manifestation of AIDS dementia. Recent findings indicate that HIV-related dementia is commonly a benign phenomenon with some similarities to other forms of dementia. One important difference may be the extent of self consciousness about, or insight into, the intellectual changes involved shown by people with HIV-related dementia. If so, special sensitivity to this will be required by staff and carers. There is an urgent need for the development of a manual for the care of HIV cognitively impaired people.

Psychiatrists need to be further involved, their training and expertise expanded, and their service accessibility and consultation roles taken up fully. This is a key area of psychiatric responsibility which needs to be addressed in terms of future and present service implications.

There is also a need for psychologists to develop their expertise in patterns of neuropsychological assessment and monitoring, and to participate in case management. Social work services for support and care systems,

occupational therapy in roles such as functional assessment and management are all currently important and may need to be further development in the future.

All involved health care professionals need to be educated in the complex psychological and psychiatric aspects associated with HIV infection. General education is needed for primary care workers, and high levels of skill and knowledge needed for psychiatrists and other specialised mental health professionals.

Efficient and integrated provision of the mental health component of care is likely to be of benefit to the whole community, and is essential to future service and human resource planning.

Possible policy components

- Determine the human resource and service requirements arising from neuropsychiatric aspects of HIV infection.
- Educate all involved in the care of those infected about the psychological and psychiatric aspects of infection.

4.4.4 Location and organisation of treatment

Patients requiring treatment for HIV-related illnesses will appear in all areas of medical practice and throughout the whole health care system. Some will require treatment for conditions not related to HIV infection, and others will be treated for illnesses which at first are not recognised as being due to HIV.

Except in a few small areas where teaching hospitals have departments of community practice or the equivalent, it would be organisationally difficult, needlessly expensive, and alienating for the patient and family to have hospital based units providing 24 hour a day services for patients at home with HIV-related illnesses.

General medical practice will be the main service through which HIV-related illnesses are first diagnosed. Already in New South Wales about 70 per cent of all requests for HIV tests come from general practitioners.

Unfortunately the present arrangements for updating the medical knowledge of general practitioners are generally inadequate. Although there is much readily available published information about HIV-related illnesses, this is one of many complex medical problems where there is no fully satisfactory substitute for direct practical experience.

As HIV infection and consequent illnesses spread, and hospital based special units dealing with HIV infection become more numerous and have more

staff and patients, it may be necessary to sponsor special short training courses in these units for general medical practitioners. This would provide grounds for locating all clinical units in teaching hospitals.

In addition to the early recognition of HIV infection, general practitioners will have a major role in the non-institutional, community based care of people with HIV-related illnesses. The later stages may involve the continuation and monitoring of complex drug therapy and, in some cases, terminal palliative care. So the person's general practitioner should be a member of his or her case management team.

General practitioners and other community based health care providers may need to develop closer liaisons with the local or regional special HIV treatment units than is generally necessary for other forms of illness. This in turn raises issues concerning the possible need for regionalisation of hospital based treatment services for patients with HIV-related illnesses.

With most illnesses requiring specialised advice or care, general practitioners refer their patients to specialists or special units. A general practitioner may refer patients to specialists working in many different locations and hospitals, and a specialist may have patients referred from a very wide area of a State or even from other States. This pattern of referral may have particular disadvantages if the condition being treated is complex. Specialists may be inclined to keep patients under their direct supervision, resulting in the excessive use of expensive inpatient hospital facilities.

The challenge of HIV infection in Australia could perhaps be turned to advantage in palliative care generally through promoting joint short courses for both general practitioners and non-medical community health staff at local specialised HIV treatment units.

HIV-related illnesses may justify the establishment of special HIV treatment units in all major and many medium sized general hospitals in rural areas. A new subspecialty of internal medicine is already developing informally and may eventually require formal recognition. However, because all the major clinical specialties will have to deal with HIV-related illnesses and require ready access to expert advice, such special units should be kept as integral parts of general hospitals.

One argument which may be advanced in favour of establishing separate hospitals for people with HIV-related illnesses is that the concentration together of many patients and staff to care for them would create the critical mass of talent and facilities needed for research into the management of such illness. The application of new knowledge in health care may be delayed or inefficient when there is no one at the cutting edge of knowledge in close and regular contact with the physicians and surgeons who can apply it in their daily work. It is preferable to promote clinical research into the treatment of HIV-related illnesses in general hospitals.

Day care centres are an important adjunct to both institutional and home care services. Such places could provide facilities for lengthy medical procedures such as infusions, and for counselling and social security advocacy, recreational facilities and a central contact point for self help groups.

Whilst specific AIDS hospices may be necessary, it is more useful to develop a range of non-institutional services which include home based hospice care, a day care centre, supported accommodation and short-term unsupported crisis accommodation, and to provide access for patients to existing hospices.

Possible policy components

- Develop a network of service provision to deal with the consequences of HIV infection to include inpatient hospital wards, specialised treatment units, outpatient services, home and hospice palliative care settings and day care services.
- Locate clinical units for people with HIV-related illnesses in general teaching hospitals only, or in all hospitals.
- Establish separate facilities to provide hospital and hospice care for people with AIDS and other HIV-related illnesses.
- Treatment services to be carried out by specialists in conjunction with general practitioners and other community health care providers.

4.4.5 Planning for service delivery

The planning of services for people with HIV infection cannot take place in isolation from broad service delivery planning.

As knowledge of the incidence and the progression of HIV-related illnesses increases, planners will gain a better understanding of the prospective demand for health and community services and the requirement for differing levels of service intensity. Detailed analyses of the service requirements of those affected by HIV need to be undertaken so that the appropriate responses to service needs can be identified.

The complexity of needs will require a continuum and diversity of services. An inventory of existing health and care services, either as dedicated or integrated services, needs to be developed, assessed and service gaps identified. An extended needs assessment, including human resource requirements, should be undertaken and compared with the health and care services inventory to predict future demands on services and identify new program needs.

The use of existing services raises the further question of whether they should employ specifically HIV-trained staff to serve the needs of what may be a small percentage of clients, or whether generalist staff should be trained to deal with all clients. Any community service which works with those infected by HIV will need to educate and counsel its workers to assist in overcoming fear or discomfort and be able to respond to a range of problems, physical, mental, emotional and economic.

The responsibility for service delivery will be determined by existing service delivery infrastructures. State governments have responsibility for delivering health services through the hospital system and in the community. The Commonwealth shares responsibility for home and community care services and services to people with disabilities.

The inclusion on planning bodies of spokespeople for those infected will assist the development of appropriate and responsive programs.

Possible policy components

- Analyse service requirements for those infected with HIV.
- Identify requirements which can be met through existing services.
- Establish separate services if required.

4.4.6 Human resource planning

Detailed human resource planning is needed across a broad range of disciplines to ensure that the specialist medical, volunteer and counselling staff are available as case numbers increase.

At the moment, most of the case load for HIV infection is being shared among a small number of general practitioners and medical specialists. This situation cannot continue much longer because of the enormous personal strain it imposes and because of the predicted increase in case loads.

However, it cannot be assumed that sufficient staff in all the required disciplines will be attracted to this area of work. There are indications in the United States that many students entering medical schools are choosing not to study specialties with a heavy involvement with AIDS patients. Hospitals in areas of high incidence of HIV infection are having trouble attracting staff and medical students. There is also some indication that university students are choosing disciplines other than medicine because of a reluctance to face the infection. The possibility of a similar response in Australia needs to be anticipated.

Volunteers are the other major group to be recruited, trained and given continuing support in their work. Once trained, these people will need to

receive continual updating on latest developments and access to practical experience and assistance in identifying potential problem areas.

The determination and application of strict limits to case loads is needed to protect personnel.

Possible policy components

- Plan future human resource requirements for the care of infected people.
- Determine case load limits and procedures for when limits are exceeded.

4.4.7 Training requirements

Short, medium and long-term training requirements need to be identified, proper accreditation procedures agreed on, and the skills of those currently involved in HIV work recognised.

A number of currently employed professionals in a diverse range of disciplines would consider HIV-related work, as long as short-term inservice training was available. They could receive some form of academic or professional credit for any study undertaken.

Significant changes are needed to current curricula in training colleges and universities, from first year of training to graduation. The already full nature of curricula in relevant areas will make this difficult. Curricula should be designed in collaboration with the teaching hospitals involved in HIV care and offered to all students.

The provision of credit or other appropriate means of recognising the experience and knowledge gained by doctors, counsellors, nurses and other health care workers in the HIV area should be examined. Such skills are not acquired through current education courses. If HIV management is to attract and retain people who are career-oriented, it is reasonable to offer them the opportunity to qualify for an appropriate professional certificate.

A great deal of current knowledge about HIV is still not written down. A major emphasis in training should be the release of experienced professionals and other related workers to produce a series of information and practical care manuals.

Continuing training and updating for those involved in HIV work presents a challenge. Some form of information clearinghouse needs to be established with adequate resources. This clearinghouse would collect and disseminate all information needed for case management and service delivery and by workers for their own purposes.

Possible policy components

- Develop short, medium and long-term training systems, pre-service and inservice, to cope with current and future needs in the HIV service delivery area.
- Develop HIV-related curricula.
- Credit HIV-related work by health care workers as part of their training.
- Establish a clearinghouse for information about HIV for health care workers.

4.4.8 The role of community groups

Community based organisations have played, and will continue to play, a critical role in the provision of HIV care, support and education. These organisations need to be expanded to cover all groups at increased risk of infection. Their ability to respond to community needs will depend on continuing and increased financial assistance from all levels of government.

Community groups will be faced with increasing case loads, demands for new kinds of services in different settings and an increasing life expectancy of people with HIV-related illnesses.

In order to respond, community groups will need to have long-range strategic plans with clear objectives and achievable goals and regular funding. Without secure funding, it will not be possible to recruit the required workers.

The challenge for community based organisations will be the development of professionalism whilst maintaining a democratic and volunteer base. Flexibility, accountability, an openness to new ideas and an ability to gather good data and use it in designing programs will be needed.

As more community groups become established, communication with a growing number of other interested parties will be essential. This will help them obtain a more diverse funding base, access to new volunteers and a clearer definition of what the community group's skills are and where the organisation fits into the continuum of care.

Community groups will face many other challenges. Specific skills workshops may be required and good management will be necessary for proper internal operation of rapidly growing community based organisations, and for securing funding and support.

Community based groups will also need to adapt service delivery over the next few years: inner city models will not work in outer urban and rural areas. Special attention will need to be given to emerging problems, including local physicians and hospitals who may be reluctant to get

involved, volunteers who may not want to be publicly identified, and lack of access for people with HIV infection to the latest treatments.

Possible policy components

Continue support and funding from all levels of government to community based organisations.

Community based organisations to develop flexible management and strategic plans.

4.4.9 The role of volunteers

The role played by volunteers in helping provide care, support and education about HIV needs to be recognised and supported. A mixture of professional and volunteer services will be necessary in the coming years and recruitment, training and internal support structures should meet the different capabilities of these groups. This mixture of service providers will have ramifications for the management of clinics, hospitals, community based organisations and government departments.

Most people affected by HIV infection are cared for and supported by family, partners and friends and there is every expectation that this situation will continue. Volunteer care organisations are a vital source of advice and support for this informal network. They also provide positive role models for other members of society.

However, volunteers have particular needs and a Volunteer Code of Practice has been developed by the Victorian AIDS Council in 1988 which recognises that volunteers have the right to clear management guidelines and processes, adequate support, recognition and respect for their contributions, to be involvement in decision making and policy formulation, and the right not to be exploited.

Volunteers working for an organisation have a responsibility to work cooperatively within the organisation, to undertake the training it provides in order to develop appropriate personal skills and to maintain the confidentiality of any information they gain. Organisations have a responsibility to provide this training.

The organisation should make professional counselling available to volunteers involved in care situations. Active participation by infected people in providing volunteer care for the sick can increase caring skills and personal knowledge. However, it is essential to make sure the volunteer is able to cope. Caring for people who are sick or terminally ill is very stressful [Crooks 1988].

Voluntary care reduces pressures on the hospital and hospice system and provides an extremely cost-effective form of service delivery. Not only are the number of days spent in hospital reduced but also the cost of care in other settings.

Volunteer work also assists in promoting tolerance and understanding of the issues throughout the wider community.

Legal liability of volunteers

The work of volunteers and voluntary agencies should not be curtailed from the fear of possible legal consequences. Litigation has been reported in the United States in which the next of kin have sued voluntary workers or their organisations following the death of a client. There is a possibility of similar action being taken in Australia against volunteers and voluntary organisations.

All workers, voluntary or otherwise, have a legal responsibility for the standard of their work, in the sense that they are professing a capacity to do the job which they have undertaken according to a level of skill which might reasonably be expected from the general body of experienced people pursuing the particular activity [NACAIDS 1986].

This responsibility may extend to situations where a volunteer might be called on to counsel and to advise clients on personal, domestic, family, and financial matters, and indeed, in some cases, to take over the management of the client's financial and business affairs.

Voluntary workers should, as far as possible, work under the auspices of a voluntary organisation. Such an organisation could become incorporated and allocate funds for appropriate insurance policies, making sure that there is a properly drawn up indemnity agreement under which the organisation is obliged to cover the cost of any damage that the volunteer might suffer, or that the volunteer might do, in the course of caring for HIV-infected people.

General liability insurance in this area might prove expensive and difficult to obtain. Consultation could be sought with the insurance industry to ensure that appropriate insurance cover is available.

A NACAIDS working party on guardianship and volunteers made a report to the Commonwealth Minister for Health in December 1986. The study noted that many volunteers find that they become de facto guardians of the people they are helping and recommended that consideration could be given to setting up an official guardianship scheme. The Victorian legislation on guardianship [Victoria, Parliament 1986] was cited as the most relevant basis for legislation for this purpose.

Possible policy components

- Voluntary organisations to become incorporated bodies to enable appropriate insurance to cover the organisation and its associated volunteers.
- Extend workers compensation provisions to provide protection for health and welfare voluntary workers.
- Legislate to indemnify volunteers from liability for negligence in the course of providing services.

4.5 Legal protection for infected individuals

Two major areas of concern relating to the rights of individuals are the protection provided by the law from unjustified discrimination and protection from misuse of personal information. The rights and responsibilities of infected people, health professionals and the community in the context of such issues as testing and informed consent, responsibilities to partners and other transmission contacts and in matters involving health care workers have been discussed.

Confidentiality

The need to maintain confidentiality of personal HIV information, both for the prevention of discrimination and to eliminate the substantial disincentive of any perceived threat to confidentiality which may deter people from coming forward for testing, counselling and treatment, has been discussed in Section 3.3.1.

There are currently a number of legal provisions relating to unjustified disclosure of personal information, including common law actions for the torts of negligence or defamation, actions in equity for breach of confidence, and statutory requirements for confidentiality of particular information.

Under existing law a patient would need to demonstrate actionable damage was suffered as a result of disclosure of information in order to establish a case of negligence, or breach of contract by a medical practitioner.

In cases of action for defamation, truth of the published information is a complete defence under common law, but in all States and Territories except Victoria and the Northern Territory it must also be shown that the public interest was served by publication.

The torts system has a number of deficiencies in its capacity to protect confidentiality of personal information. The remedies provided, usually damages, may not be as appropriate as obtaining an injunction against further dissemination, and in most cases the subject of the information will not be aware of the extent to which it is spread. The long time involved, personal trauma and high cost of private litigation also contribute to difficulties in the use of such actions.

An alternative remedy is by way of an action in equity for breach of confidence. This would apply to instances where confidential information is disclosed without the consent of a person to whom a legal duty of confidence is owed, or for a purpose inconsistent with the purpose for which the information was originally acquired. The usual remedy is an injunction against further disclosure, although damages have been awarded in some

instances. A number of defences exist for such actions, including public interest and implied consent. However, the extent to which each can be used in cases relating to HIV information is uncertain and will require resolution by the courts.

In general, civil actions for misuse of personal information suffer from a number of uncertainties and limitations, and in any case can operate only after disclosure has occurred and been detected.

Effective methods for protecting confidentiality must rest with adequate education for all people who handle confidential information, with the promulgation of guidelines and codes of practice and penalties for misuse of personal information. Procedures and guidelines will not of themselves have sufficient impact to secure confidentiality. In view of the serious consequences of the disclosure of a person's HIV status, some legislative reinforcement may be necessary.

At present there are provisions in Commonwealth and State legislation which establish limitations on the disclosure of particular information in the public sector. These limitations are not sufficient to ensure proper confidentiality in many circumstances and may need to be reconsidered or clarified in regulations to address the problems arising with HIV.

Special legislative amendments relating to HIV infection could be adopted in all jurisdictions. One example is provided by the provision in the recent Victorian Health General Amendment Bill which requires a person who in the course of providing a service is given information that a person has been or is required to be tested for HIV, to take all reasonable steps to develop systems to protect the privacy of that person.

Alternatively, privacy and confidentiality issues raised in relation to HIV could be considered in a broader context for legal reform. In the past, options for reform in the area of legal protection of confidentiality have included the creation of a general tort of breach of privacy or confidence, statutory clarification or extension of the existing law of breach of confidence, and the enactment of special legislation concerned with privacy issues. These options deserve careful consideration, but it would not be appropriate to provide detailed legal arguments about them in this Paper. Such arguments may be found, for example, in the report on privacy by the Australian Law Reform Commission [ALRC 1983].

This report did not find it necessary to recommend the creation of new torts of breach of privacy or confidence. However, it did recommend an extension of the right to enforce a duty of confidence at all times to the subject of the information. It also recommended the establishment of a Commonwealth statutory guardian for privacy and a Privacy Commissioner within the then Human Rights Commission with powers to address privacy issues in the Commonwealth public sector and the private sector in the ACT.

The report took the view that privacy was also the responsibility of State governments. The Commonwealth has currently before the Parliament a Privacy Bill which would regulate the collection and handling of records of personal information by Commonwealth departments and authorities.

Privacy Committees have been established in New South Wales and Queensland to provide guidelines and recommendations on privacy related issues, and to investigate complaints of breaches of privacy. The other States could consider establishing similar bodies to promote awareness of confidentiality requirements and to develop policies for the protection of personal information.

Discrimination against infected people

Cases of discrimination against people known to be infected, people believed to be at risk of contracting HIV, people known to have taken the HIV test, members of their families, and health care workers have already occurred in Australia. Complaints received by the New South Wales Anti-Discrimination Board since 1985 on HIV matters have been related to refusal of health, welfare, education, housing and other services and employment. Discrimination has taken a range of forms including dismissal, forced transfer, attempted segregation, abuse and physical violence.

Most discriminatory practices and attitudes relating to HIV infection have no scientific basis. They are often based on ignorance, which in many cases can be corrected by education and counselling. However, it must not be assumed that education will of itself change attitudes in all people. Some official body may be needed to investigate instances of discrimination and to encourage conciliation. If conciliation is not possible, recourse to penalties under the law for unjustified discrimination should be available.

Only in Victoria has the government enacted legislation to allow people who face HIV-related discrimination to seek redress. Legislation in some countries proscribes discrimination related to AIDS in employment, housing, provision of medical and dental services, business establishments and city facilities.

In some Australian States, general anti-discrimination laws may provide limited protection in certain situations. In Victoria, New South Wales and South Australia, it is unlawful to discriminate on the grounds of physical impairment in areas such as employment, education, accommodation and supply of goods and services. The physical impairment definitions in the South Australian and New South Wales Acts are likely to apply only when a person clearly has an HIV-related illness. It is not clear whether they cover people who are HIV-infected but asymptomatic, and they do not cover imputed infection.

It is also unlawful to discriminate in New South Wales and South Australia on the grounds of homosexuality or presumed homosexuality. Because HIV-related discrimination is likely in many cases to be linked with more

general discrimination against homosexuals these provisions, where they operate, may serve to protect the majority of HIV-infected people. However, they will not protect other HIV-infected people, nor will they protect the partners or families of infected people, or health care workers.

People who are thought to be at risk of infection are not specifically covered by any anti-discrimination provisions. Thus an infected person's spouse, child or partner who suffers discrimination has no redress.

Possible policy components

- Consider legislative means for ensuring confidentiality including legal requirements to develop systems to limit the dissemination of confidential material.
- Establish, extend or clarify anti-discrimination legislation in all jurisdictions, either specific to HIV-infected people or covering them under general provisions, including provisions against discrimination against family or carers of infected people.

Objective 3:

To educate and to prevent infection of people who care for HIV-infected individuals

5.1 Education of carers of infected individuals

Health care workers and other carers of infected people need specific skills to provide appropriate care, to participate effectively in managing HIV infection and to implement protective and supportive work practices. Attitudinal and environmental barriers to appropriate practices; that currently exist in many health care settings, should also be addressed. Access to current information about referral agencies, organisational techniques for small groups and communication skills suitable for patient advocacy is needed.

The term 'health care worker' applies to a diverse range of occupations for which the training prerequisites vary greatly. Education programs for health care workers should recognise other occupations as having a health care role: ambulance officers, parole officers, correctional officers, police officers, fire fighters and others.

Education programs are needed by all staff, including kitchen and cleaning staff, in health care settings where infected people are treated.

HIV has engendered a widespread fear to which all people, including health care workers, are vulnerable. Fear among health care workers is understandable, partly on the basis of an occupational risk of infection, but also because of the consequences of infection which they see in their patients. This fear needs to be addressed through education and, in some instances, counselling.

The particular needs of close family and friends and workers in community services are likely to be best met by community based education programs and support groups which concentrate on the source of personal fears and prejudice, on the realities of transmission risks, on household and personal hygiene requirements, on the management of emergencies and accidents, on dealing with loss, grief and anger and on health, emotional and financial support needs.

Carers, family and friends also need counselling and support if they are to be able to continue to function as community helpers. They live with the consequences of infection, and studies show that they run a higher risk of developing chronic psychological disorders than do infected people themselves [Miller 1988]. Counselling is required to support and assist them.

Health professionals required to work with HIV-infected people will be exposed to increasing numbers of dying patients. In order to reduce psychological trauma and staff turnover in health professionals, creative programs for staff support will need to be developed.

Carers, and their families, may have personal and professional belief systems which will influence their understanding of, and ability to participate in, the management of HIV-infected individuals. For instance, antagonism to homosexuals or intravenous drug users, or rigid adherence to particular professional practices, may create situations where the ability to participate effectively in the management of HIV is hampered. These issues can be addressed effectively within an appropriate education program.

The spread of HIV has ushered in a new approach to infection control which challenges practices long adhered to by many health care workers. The rigorous application of infection control procedures will require a significant shift in the way infection control is perceived by those practising it, and by those responsible for communicating policy.

For example, vast quantities of literature outlining HIV infection control procedures have been distributed to laboratory and research staff in Australia. In spite of this, guidelines to control laboratory infection have not been rigorously applied. Providing this information is important, but environmental and attitudinal barriers need to be changed through education.

Equally, for those working in non-clinical health care, problems may arise on how to interpret infection control guidelines appropriately. These people may need assistance in learning how to apply them.

If carers are to participate in the education of the general community on HIV, their contribution needs to be part of the overall integrated education strategy. Otherwise, they could deliver inconsistent messages to the community, damaging the credibility of messages from other sources.

The delivery of systematic, occupationally specific programs to health care workers will improve the general response to the epidemic.

Possible policy components

- Provide adequate and appropriate HIV-related education as part of the accreditation process in institutional settings such as hospitals and pathology services.
- Provide similar programs for non-institutional and less clinical settings, such as residential drug and alcohol treatment agencies and home care services.

5.2 Protective work policies and practices

All appropriate steps should be taken to protect from occupational transmission of HIV all persons who are caring for, or providing health services to, an HIV-infected person.

The objectives of any protective work policy should be to prevent transmission of HIV from patient to carer, from carer to patient and from patient to patient. The policy must be capable of implementation and enforcement, economically feasible, and should pose a minimal risk of adverse medical, legal or social consequences to the patient, the health care provider and the institution [Gerbeding and Henderson 1987].

Infected individuals are cared for in settings which include hospitals, hospices, outpatient facilities, the home, day centres and other community situations.

People who care for infected individuals undertake activities involving contact with patients, and probably their blood and other body fluids.

The risk of acquiring HIV infection from work activities in any health care setting is very low. There have been very few cases of transmission relative to the large number of people exposed to HIV-infected blood or other matter in the course of their work.

The extent to which this already low risk can be further reduced depends on how rigorously infection control and accident prevention procedures are applied.

However, the low risk of HIV transmission may be increased by health care workers failing to observe accident prevention procedures or infection control guidelines. A study undertaken at the San Francisco General Hospital, which has considerable experience in the management of illnesses related to HIV infection, provides evidence of the need for strict application of infection control guidelines and accident prevention measures. Of a group of health care workers who cared for HIV-infected individuals for one year or more, 35 per cent sustained potentially infective exposures to HIV-infected body fluids and 56 per cent used inadequate precautions when dealing with a person with AIDS or with specimens from their patients. All staff had access to extensive education on infection control procedures. The relatively poor compliance with recommended infection control procedures is disturbing [Gerbeding et al 1987].

Occupational transmission in health care settings has been reported in only a small number of cases (see Table 4). The increasing prevalence of HIV increases the risk that health care workers will be exposed to HIV-infected

material, especially where protective precautions are not followed for all patients.

5.2.1 Infection control procedures

Since clinical examination, medical history and testing are not sufficient to identify reliably all patients infected with HIV or other blood borne pathogens, the basic feature of programs to control and prevent HIV transmission in health care settings must be the consistent routine application of infection control procedures when handling blood, body fluids and wastes; the use, if appropriate, of alternatives to invasive diagnostic and therapeutic procedures; and the proper use of sterilisation and disinfection.

All health care establishments should develop their own infection control guidelines for communicable diseases, including HIV infection, and should ensure that these are consistently and routinely applied. The principle of universal infection control procedures has been endorsed by the Centers for Disease Control [CDC 1987b]. The AIDS Task Force strongly endorses this principle as the ideal standard.

However, experience with the use of similar guidelines, either for general application or concerned with other infectious diseases such as hepatitis B, has shown that this principle is difficult to implement, especially where the risk to the carer is perceived to be low.

In each workplace, or category of work, procedures should be tailored to the activities of the people working in that setting. Applied procedures must be developed with the active involvement of health care and laboratory workers, their union representatives and management. Leadership and motivation through example are important factors in gaining support for effective infection control guidelines.

Simple procedures to deal with accidental exposure will include the covering of sores and wounds, effective cleaning of the body and contaminated surfaces, and procedures to minimise accidents. Procedures for the removal of blades, needles, sharp instruments, contaminated linen and clothing, containers and clinical materials may need to be improved. In some cases, currently used procedures will be appropriate.

The rigorous application of infection control procedures in all health care settings would represent a significant change in the practice of most institutions and of most health care workers. A strong commitment of resources for staff consultation, training and retraining, establishment and enforcement of the procedures, and compliance monitoring would be necessary.

There are significant advantages in rigorously applying infection control and accident prevention procedures. Compliance will reduce the transmission of all blood borne and other disease causing pathogens. The precautions will also minimise the risk of discrimination against HIV-infected patients and health care workers.

Universal infection control procedures are essential at all times when dealing with patients who require urgent treatment in emergency settings and outpatient departments irrespective of whether their infection status is known or not [AIDS Task Force 1988].

Health care establishment staff

Health care establishment staff, particularly hospital staff, will be placed at greater risk of infection if accident prevention and infection control procedures are instituted selectively. Should this happen, staff on wards known to contain HIV-infected patients may be at less risk of infection than staff on other wards.

Infection control procedures should be appropriate to the actual risk of infection. Excessive precautions are offensive to those infected and their visitors and can hinder the execution of established routines, increasing rather than decreasing the risk of infection.

Consideration could be given to making the rigorous application of infection control procedures a condition of hospital accreditation.

Laboratory and research workers

All those handling blood or body tissues should treat such specimens as potentially infective. One study of laboratory practices relating to the handling of serum or plasma specimens recommends that all blood specimens should be handled as if they are infected, regardless of biohazard labelling. In this study, only 67 per cent of specimens with HIV antibody and 28 per cent with hepatitis B surface antigen bore biohazard labels. The study argued that if complacency is fostered by the use of biohazard labels, their misuse may increase the risk that laboratory and research staff will be exposed to HIV, as well as to the hepatitis B virus [Handsfield et al 1987].

The general laboratory and research procedures outlined in the Infection Control Guidelines issued by the AIDS Task Force [1988], if followed, will minimise or eliminate the risk of occupational infection.

Changes to work practices may be needed and education will be necessary to raise standards of infection and accident control to safe levels. Training courses in schools and universities need to incorporate the reasons for and the proper application of infection control procedures into their curricula.

Consideration could be given to study tours to observe infection control practices elsewhere, and to bringing overseas infection control and laboratory staff to tour Australian facilities.

The rigorous implementation of infection control and accident prevention guidelines is the responsibility of all managers of potentially hazardous work environments. Leadership by example is essential.

Autopsies

In some States, autopsies on the bodies of those who have died from an HIV-related condition are not carried out because of the concerns of workers. Although there have been no cases of HIV infection attributable to occupational exposure among pathologists, mortuary technicians or other staff, it is important that adequate and appropriate precautions be taken. In the majority of cases it will not be possible to know whether a body contains HIV infection so appropriate infection control procedures should be taken routinely in all cases. Where HIV infection is known, the procedures recommended by the National AIDS Task Force [1988] should be followed. All staff involved in autopsies should be given appropriate education about HIV infection and the implementation of the necessary procedures. Each State should ensure that special autopsy facilities are available to deal with cases involving any dangerous infectious diseases.

Police and emergency workers

There is concern among police and emergency workers about occupational transmission. This concern may stem from misinformation and limited understanding of infection control procedures.

Specific concerns include:

dealing with body fluids where blood-to-blood or other high risk contact is possible;

body searching, in particular cavity searches, and handling human remains;

handling people who may be at risk of HIV because of their lifestyle or behaviour; and

handling people who may be violent, intoxicated or otherwise not in control of their behaviour.

The New South Wales Police Force has recently introduced a HIV education program praised by people working in the field. Other States could consider introducing similar programs.

Home and community settings

Many people with HIV illnesses will be cared for in home and community environments and appropriate protective procedures need to be observed. The pamphlet, Care of a Person with AIDS At Home [ANCA 1988c] and the AIDS Task Force Infection Control Guidelines [1988] set out such procedures.

Transmission has not occurred through people with HIV cooking, eating, washing and using laundry facilities in these settings. Razors and toothbrushes should not be shared. Needles used in home care treatment should be properly discarded into puncture proof containers. Hands should be washed after cleaning, toiletting and before eating or smoking. Body fluids must be properly dealt with.

Carers must ensure that any open wounds they have are covered.

People managing municipal and voluntary home help services, hospital domiciliary care services, community nursing services, volunteer care programs and self-help groups have taken responsibility for the dissemination, explanation and implementation of these procedures for infection control in domestic and community environments. These organisations are well placed to provide accurate information and also to allay fears and correct misconceptions and false information.

Implementation of the recommended precautions

All people who work in health care settings require an appropriate education program which will enable them to implement recommended precautions.

Managers and supervisors must lead by example. Management and union representatives can make sure, by supporting and encouraging protective working practices and accident prevention measures, that the health of people who work with and care for individuals with HIV infection is not compromised.

All people who care for such individuals must have access to the necessary equipment and supplies so they can implement the recommended precautions. Consideration needs to be given to making these available free of cost or on a subsidised basis to family members, other individuals caring for an infected person at home and to voluntary organisations so engaged.

Documentation of training and, possibly, certification in infection control may be advisable to protect institutions against claims of negligence as a factor in occupational transmission.

Management of staff exposed to infectious material

Procedures need to be developed for managing the exposure of any staff in an establishment to a risk of HIV infection. Reporting procedures of exposures need to be firmly established in the best interests both of the

worker and of the establishment. Staff should receive immediate counselling, including detailed discussion of the evidence requirements if worker's compensation is later to be claimed. Evidence is required that previous non-occupationally related exposure had not occurred and might be met either by testing or by the taking and storing without testing of a blood sample.

Some time after exposure, staff members should be consulted and counselled about whether they wish to be tested for HIV infection. If a negative result is obtained, the same procedure could be followed at a later date. This procedure ensures that proper counselling is provided and that all testing for occupational transmission is voluntary, whilst it assists any subsequent compensation claim.

Management of HIV-infected health care workers

Properly implemented infection control procedures will protect patients and other staff from the risk of transmission from infected staff and will at the same time protect infected staff from exposure to other infectious agents. Health care workers with impaired immune systems should be counselled about the potential risk to them of taking care of patients with any transmissible infection.

Whether infected health care workers should perform invasive procedures needs to be considered. The issue could be dealt with on an individual basis by the worker's personal doctor and appropriate staff of the employing institution.

Monitoring and evaluating protective policies and procedures

The establishment of monitoring and evaluation procedures must be part of the system of protective policies and procedures, so that errors, misunderstandings or neglect of guidelines can be identified and appropriate counselling, retraining or disciplinary measures initiated. These procedures should also be able to identify recommended precautions which prove inappropriate in a particular situation.

Monitoring of workers who may place themselves or others at risk, and also of institutions which may fail to use adequate infection control and accident prevention procedures, must occur. Appropriate sanctions could include loss of hospital accreditation.

Possible policy components

- Apply universal infection control and accident prevention procedures.
- Develop and implement infection control and accident prevention procedures tailored to the requirements of each health care environment.
- Make hospital accreditation conditional on the rigorous application of infection control procedures.

- Provide access for police and other emergency workers such as firefighters and ambulance personnel to comprehensive, factual and practical education about transmission of HIV and its prevention.

5.2.2 HIV testing in health care settings

A number of health workers have advocated testing of patients prior to medical treatment, on admission to hospital, and particularly before surgery.

They argue that identifying infected patients will reduce the risk of transmission in ensuring infection control precautions are taken with these patients. A number of surgeons believe that special procedures, not applicable or advisable for other patients, should be used for HIV-infected patients to reduce the risk of accidental exposure. Similar arguments have been made for screening patients in other settings.

It should be noted that many of the arguments based on the risk of transmission from patients to health care workers could also be used to advocate testing of health workers to protect patients.

Various assessments have been made of the risks of occupational transmission, particularly in surgical procedures, based on numbers of skin punctures, prevalence of infection in the population and the risk of infection following skin penetration [Hagen et al 1988]. These calculations show the risks to be very low. However, the consequences of HIV infection make the risk relatively greater than that associated with other less lethal pathogens [AIDS Task Force 1988].

It is important to note that of the 15 documented cases of occupational transmission in health care settings notified to CDC (see Table 4), all occurred in situations where the HIV status of the patient was already known. There is no evidence that knowing a patient is infected with HIV will prevent transmission, even in surgical or other high risk settings [Gerbeding and Henderson 1987]. Clearly the primary focus should be on accident prevention and infection control.

Testing has practical limitations. These include the inability to detect infection up to about three months after initial infection. In addition, it is clearly impractical to require testing in cases requiring emergency surgery. The risk of transmission through surgery can never be entirely eliminated, but it is already very low.

Current barrier precautions for surgery and other high risk settings appear to protect personnel, including operating room personnel, effectively [Hagen et al 1988]. More care may need to be taken in handling all potentially infectious materials [Lynch et al 1987].

Health workers, particularly surgeons, should have the maximum relevant medical information for providing appropriate care, and in some cases there may be medical value in knowing HIV antibody status of a patient. However, if finding an antibody positive person through testing would not lead to a change in procedures, the test is unnecessary. The normal requirement of informed consent for obtaining medical information should apply.

Identifying HIV-infected people can expose them to damaging consequences and it can have a deleterious effect on the quality of medical care received. Already in Australia health care providers have refused to provide care to HIV-infected patients, refused to perform indicated invasive procedures and have transferred patients to other facilities.

Concerns have been expressed about maintaining confidentiality in health care settings. If testing policies are instituted, it is essential to ensure that only those who have an agreed need to know are aware of the results of the test. Adoption of such policies should provide for institutional penalties for breaches of confidentiality.

Routine testing would incur considerable expense, both in the cost of performing and confirming the tests and for the associated counselling, education and follow-up of patients. Resources could be directed to more effective methods of limiting transmission in health care settings.

It is the responsibility of public health authorities to protect those caring for HIV-infected people from the small but definite risk of occupational transmission. It would be a matter for concern if testing patients undermined the acceptance of consistent protective infection control and accident prevention procedures, or deterred people at risk of infection from contacting health personnel for fear of discrimination.

Possible policy components

- Routinely test all health care workers and patients, either on admission to hospital or before providing health care such as major surgery.
- Actively encourage voluntary testing and the rigorous application of infection control and accident prevention procedures.
- Involve public health authorities, community groups and those calling for testing in the determination of an agreed policy.

5.3 Supportive work practices

People caring for HIV-infected individuals assume a degree of responsibility and face a range of problems greater than that encountered with most other patient groups [Volberding 1988].

It is important that proper supportive work practices be established to ensure that both employed and voluntary staff are available. Without these practices, the physical and psychological stress which carers experience could lead to patients not receiving the care they need, to medical practitioners and nursing staff being reluctant to take up positions in certain hospitals or to train in certain specialities, and to potential medical and nursing students turning to non-medical disciplines.

This disease has increased awareness of the fact that medicine is practised in a social context. Since HIV infection cannot be isolated from its associated social, legal and ethical problems, it does not fit easily into models of medical care which have evolved in recent decades.

Little formal training in medical ethics is given to health care workers, yet the ethical questions associated with HIV infection are complex and subtle. They span the care of the terminally ill and the demented, the allocation of resources between AIDS and other serious illnesses, the extent of the duty of care and the duty to warn, the cluster of concepts concerning consent, privacy and confidentiality, isolation and quarantine, pregnancy and abortion, the interplay between personal moral or religious beliefs and care and compassion, and the role of the concerned practitioner.

Medical practitioners and other carers may feel intimidated by the medical complexity of HIV-related conditions and by the many medical and non-medical diagnostic and therapeutic approaches available. Life-threatening infections or malignancies can affect any part of the body, including the brain, and so extensive demands are placed on the skills and knowledge of doctors and of specialist teams.

Health workers often feel an engulfing fear of becoming infected with HIV. This in itself may lead to night sweats and nightmares [Shilts 1987]. These fears can exist even when the carer has realistic knowledge of the extremely low occupational risk of transmission, and may affect a carer's family and friends.

Health care workers may also share with others in our society feelings of repugnance or antagonism to homosexuals, drug users or people who work as prostitutes. These attitudes may influence patient care and are certainly a source of stress for those working with HIV-infected people.

Carers may feel unable to deal with the psychological stress of caring for patients who are young, who deteriorate physically and often mentally, whose dying is often drawn out and for whom medical science can do relatively little. Training and support is needed to maintain their confidence and effectiveness. Respite care for home or community carers themselves may be needed.

Active discussion among professional groups and associations about work related stresses among people working with HIV-infected people will lead to better support and understanding of those working in this field.

The work conditions of staff caring for HIV-infected people may be improved through measures such as shorter work hours and staff rotation. Informal or formal group sessions where carers discuss the wide range of situations and problems encountered are important.

Multidisciplinary teams, with or without HIV specialists and including volunteers, family members and friends, will maximise the quality of care to individual patients, help to spread the caring load among people with a variety of skills, and provide mutual support.

Case management models are needed to provide support across the spectrum of interrelated medical and non-medical factors.

Possible policy components

- Extend training in medical ethics to health care workers and medical students to cover HIV-related ethical issues.
- Improve working conditions for those involved in care, including shorter working hours and staff rotation.
- Involve a broad range of disciplines in the provision of care.
- Provide supportive services such as counselling and support groups to those involved in care.

5.4 Legal issues in health care settings

Health care workers and institutions need to be aware of their legal rights and responsibilities as they are confronted with issues raised in the HIV epidemic.

The responsibility of health care workers to maintain confidentiality, to ensure informed consent takes place before testing and treatment, and to provide adequate counselling, has been discussed in Section 3.3.1. There are two further areas of responsibility for health care workers which impinge on the law, both of them relating to duty of care.

The first arises when dealing with HIV-infected patients. It is to be expected that some health professionals will fear accidental infection, however remote the chances may be, and will seek to avoid duties bringing them into contact with infected patients. However, health professionals who withhold services simply because a patient is known or suspected to be HIV-infected may be subject to disciplinary action by their Registration Boards or potentially liable for negligence actions or actions under anti-discrimination legislation in New South Wales, Victoria and South Australia.

Health care workers, whether they are nurses, cleaners, dentists or orthopaedic surgeons, have a duty to protect themselves, their colleagues and patients by following appropriate and practical infection control and accident prevention procedures. These procedures have been formulated to combat diseases such as hepatitis B, which are more prevalent and more infectious.

The second issue relates to the situation faced by a medical practitioner when a person is found to be positive, but indicates that he or she does not intend to warn a partner or take precautions against transmission. The legal obligations of physicians or other health care workers to care for a third person in such circumstances are not clear, nor are the necessary steps needed to fulfil such obligations. However, they include at least the provision of adequate counselling and information to the infected patient and may well extend to warning others.

The moral dilemma facing a health professional in these circumstances has been discussed in Section 3.4.3, where it was suggested that such instances can be best handled through the clarification of options and responses in pre-test counselling sessions. If, in the course of these sessions, a person indicates a refusal to warn others or to take precautions, the health professional could suggest marital or other forms of counselling, could refer to appropriate specialist services or could notify the partner at risk under these circumstances.

Health care workers have the right to expect the institutions for which they work will ensure adherence to infection control and accident prevention guidelines which adequately protect them. They should also be able to expect understanding of the stress experienced when working constantly in the midst of a disease which produces distressing physical effects on many patients. Workers compensation law may need to be reviewed in all States and Territories to ensure that the particular risks and effects of HIV infection on health care workers are adequately covered by existing legislation.

Possible policy components

- Determine the legal rights and responsibilities of health care institutions and health care workers.
- Educate health care workers and health care institutions in their legal rights and responsibilities and in ways of meeting them.

International cooperation

6.1 International cooperation: the international political community

The spread of HIV is a growing problem throughout the world. In areas of high levels of infection, there will be significant losses in agricultural and economic productivity, a breakdown of health care systems, social organisation and support systems, and significantly increased infant mortality and dependency rates. The international political community and the development assistance community will be challenged to respond.

Australia has played a leading role in placing HIV on the international political agenda as an early and active supporter of the World Health Organization's global strategy begun in February 1987. Australia co-sponsored the resolution on AIDS at the 40th World Health Assembly in May of that year, [Appendix 2].

Early in the 42nd session of the UN General Assembly in 1987 Australia decided to seek the adoption of the first General Assembly text, Resolution 42/8, which recognised the serious threat posed by HIV, endorsed the World Health Assembly's central coordinating role in the global battle against HIV, and accepted the principle that the United Nations and its specialised agencies should respond in a coordinated way.

In May 1988 another critical resolution was passed by the World Health Assembly on the avoidance of discrimination in relation to HIV infected people and people with AIDS [Appendix 3]. Australian experts have taken part in consultations organised by the WHO Global Programme on AIDS (GPA) on issues of international concern.

At the regional level, in July 1987 Australia co-hosted with the WHO GPA an Inter-Regional Ministerial Meeting on AIDS which brought together Health Ministers and senior officials from East and Southeast Asia and the Pacific. Many countries in the region were not fully aware of the threat and the importance of developing preventive measures and education campaigns to protect their populations. The tourist flows in our region place on Australia a special obligation to alert our neighbours to the issue, an obligation reinforced by our traditional role as a provider of development assistance in the region.

The meeting succeeded in increasing knowledge about the virus and in raising the political consciousness of regional governments on the need to develop preventive campaigns in their own countries. It also assisted in developing a willingness amongst these countries to cooperate with others.

The international community needs to improve the education of those in political or policy making positions, at the national level and within the UN system itself, because this virus could pose a long-term threat to the

economic, social and political fabric of some nations in a way that no other recent major health epidemic has done. Many aspects of relations between countries, for example tourism, trade, migration, civil aviation and aid, could be affected.

The international political debate has been able to reach a consensus on the issues raised so far. However, already there have been questions involving human rights and non-discrimination in response to policies adopted by member States on, for example, the testing of international travellers. To secure a continuing effective international response, Australia needs to continue its leading role in international and regional political considerations of these issues.

Possible policy components

- Continue Australia's active role in the discussion of HIV-related issues in the international political community.
- Continue support for the work of the WHO Global Programme on AIDS.

6.2 International cooperation: the development assistance agenda

On the basis of the presently available information, governments will need to take increasingly difficult decisions in allocating scarce national resources for HIV-related programs compared with other priority areas of government activity. For developing countries, these will be particularly difficult choices [Reid 1988].

The cases of AIDS and of HIV infection are not evenly distributed. In the Third World, there are areas of high levels of infection in sub-Saharan Africa, in the Caribbean and in South America. In Australia's immediate region, few countries have reported many confirmed AIDS cases. However, there is a growing concern about the spread of the virus in a number of Pacific and East Asian countries.

Minimising HIV transmission globally will require both national and international action. Developing countries need to initiate prevention and education programs but few have the financial or human resources to do so. They are requesting assistance from the donor community but, as donor countries have learnt from their own experience, while assistance is required immediately, planning must be on a long-term basis if it is to be effective.

The pioneering work on HIV-assistance to developing countries has been carried out by the WHO GPA which has placed a major emphasis on assisting developing countries to formulate national AIDS programs. The Programme's functions are to provide technical and financial assistance to governments in developing, implementing and monitoring AIDS education activities; coordinate, promote and finance biomedical, social, behavioural, epidemiological and operations research; and to coordinate, promote and finance data collection and analysis to describe current and predict future HIV infection trends, along with associated social, economic and demographic impacts. About 60 per cent of the WHO GPA budget for 1988 to 1991 is expected to be spent on country-level support and on short and medium term National AIDS Control plans. As of June 1988, the Programme had assisted countries in the preparation of 106 short-term plans and 28 medium-term plans throughout the world.

So far, the Global Programme on AIDS has been responsible for financing most HIV-related initiatives in Australia's immediate region. WHO has drawn extensively on Australian expertise in the development of plans in fields including education, virology, immunology, clinical research and management and in the establishment of community-based groups and prevention programs. The Australian Government has announced a contribution of A$2 million to the GPA by 1990–91.

Once medium-term AIDS control plans have been prepared in individual countries, it is usual WHO practice to convene donor meetings to determine what support will be available for implementation of the plan and in what areas. Australia would normally attend such meetings in the Pacific, South East Asia and the Indian Ocean Island States and can expect increasing calls to respond to requests for financial assistance in the region.

The Australian International Development Assistance Bureau (AIDAB) has received requests for project assistance and in June 1988 issued guidelines for HIV-related assistance. These guidelines restate the decision made in the international community that all bilateral assistance must be given within the context of national AIDS programs and, therefore, in consultation with the central national AIDS coordinating body. They also require liaison with the WHO GPA.

The HIV-related needs of countries in Australia's immediate region can be met in a number of ways: through AIDAB's mechanism for the country programming of assistance to these countries; through a mechanism outside of its country program procedures; through an allocation in the budget of the Department of Community Services and Health for smaller scale, non-project assistance; and through the non-government sector.

Since the Jackson Report [Committee to Review the Australian Overseas Aid Program 1984], AIDAB has moved to channel its bilateral assistance through a country programming mechanism. The basis of this approach is an agreement reached between AIDAB and the recipient country on priority sections or areas for Australian development assistance. Requests are then received from recipient countries for project assistance within these priority areas and are accepted or rejected according to AIDAB's assessment of the viability of the project.

Few countries in the region have nominated the health sector as a priority area for Australian assistance. Countries seeking funding for HIV-related projects from Australia would have to re-negotiate their country program priorities. For all major Australian aid recipients, opportunities for this occur annually at high level consultations. However, government officials outside the health sector may not be well informed about HIV infection and the importance of early intervention.

In recognition of such potential constraints AIDAB has already set aside a regional allocation of funds ($250 000 in 1988–89) allowing funding of Australian initiated AIDS control activities in the South Pacific. This is part of the South Pacific Multi-Country Program. Consideration could be given to extending this type of funding into subsequent financial years and into the South East Asia and Indian Ocean regions.

Requests received by the Department of Community Services and Health for Australian assistance have included a significant number for reference materials for libraries, teaching institutions and clinicians, for training in

Australia for laboratory technicians, counsellors, educators and health professionals, the use of Australian testing facilities, educational materials and assistance to attend or hold expert meetings and consultations.

Small scale assistance is difficult or not cost-effective to respond to within the context of AIDAB's bilateral or multilateral assistance program. The Department of Community Services and Health is the counterpart organisation for WHO and the Global Programme on AIDS, the point of liaison for health departments in other countries and the recipient of such requests for assistance. For Australia to respond to such requests for assistance as rapidly and as flexibly as possible, Australian Heads of Missions could use discretionary aid funds in accordance with AIDAB guidelines. Consideration could also be given to the Department of Community Services and Health being given a capacity to respond to such requests.

Most effective HIV programs have been the result of a fruitful collaboration between the government and non-government sectors; this has been the case in Australia and the same can be expected in the Third World. Australian non-government organisations have already been called upon to assist in Africa. Such calls for assistance will increase, particularly as the virus spreads throughout Asia and the Pacific.

It is now generally recognised that efforts to contain the epidemic will not succeed without active involvement of the non-government community. AIDAB should encourage and support the participation of NGOs in HIV-related activities as long as they can show that these are linked to, and complement, national programs.

Non-government organisations in Australia are well suited to assist their counterparts in developing countries. They can also assist in increasing understanding among Australians of the effect of HIV in the Third World.

Within these program areas, there are two important roles for Australian non-government organisations. First, they can act as brokers between non-government organisations in Australia and those in the Third World which are seeking ways to help prevent transmission or to care for those infected. Their role would be to inform their counterpart organisations about the work community organisations can undertake, the training requirements and curricula used and the approaches developed.

The second role for Australian non-government organisations is raising issues relevant to the epidemic with their counterpart organisations and assisting in the transfer of skills.

One of the strengths of Australian aid agencies has been their programming focus on development education. A component on HIV in the Third World should be added. The rationale for this is wider than a concern for the future of the Third World. There is national self-interest: the nature of HIV and the associated modes of transmission are such that no national programs for

the containment of this virus will succeed unless a simultaneous effort is made to contain it globally.

Agencies could also provide the media with information on their initiatives, including bilateral and multilateral programs, aiming for responsible reporting of HIV-related issues in the Third World.

Possible policy components

- AIDAB to be involved in all donor meetings convened in the South Pacific, South East Asia and the Indian Ocean Island States held to coordinate support for HIV prevention and control activities.
- Continue funding HIV-related activities through the South Pacific Multi-Country Program and consideration of similar programs in South East Asia and the Indian Ocean Island States.
- Develop a capacity in the Department of Community Services and Health to respond to small-scale, non-project requests from developing countries for HIV-related assistance.
- AIDAB to encourage and support the interest of non-government organisations in HIV-related activities in developing countries.

Research to support a National AIDS Strategy

7.1 The requirement for research

Research has a vital role to play in support of a National AIDS Strategy. The success of this Strategy will depend on the quality of the research base on which it can draw to develop policies, design and implement programs and evaluate their effectiveness and impact.

Considerable research at a high standard has already been undertaken in Australia on HIV-related topics in the biomedical and social sciences. The national research effort now needs to be extended to enable it to provide further support for public health officials, health educators, community groups and others involved in Australia's response to the epidemic. This can be done both through our own research efforts and by transferring to Australia the advances made elsewhere.

Investment in research is essential to ensure the most efficient and effective use of resources to minimise the spread of the virus and to care for those infected.

7.1.1 Research goals

Research goals for a National AIDS Strategy need to be clearly defined. They could include:

1 To provide the information required to develop strategies and programs to achieve the three objectives of a National AIDS Strategy.

2 To describe the clinical manifestations and natural history of HIV infection in Australia.

3 To ensure that Australian expertise in HIV-related research areas remains at the forefront of knowledge so that new developments can be applied and evaluated quickly.

4 To participate in the global research effort, particularly in basic biomedical research which can provide knowledge essential to treating infection and limiting the epidemic.

5 To assist countries in the region, on request and in conjunction with the WHO Global Programme on AIDS, to respond to the epidemic.

7.1.2 Research priorities

Agreement is needed on priority areas in which more information is required for a reasoned analysis of policy options, for designing and determining the effectiveness of programs and for identifying factors which may affect policy implementation.

In the next five years, a great deal of information will be needed to develop and implement a National AIDS Strategy. Research priorities in this period will need to reflect the priorities of the Strategy:

prevention of transmission in those at higher risk of infection, namely homosexual and bisexual men, intravenous drug users and prisoners;

education of groups potentially at higher risk of infection if the virus spreads further beyond the higher risk groups, namely Aboriginal and Islander people, adolescents, women and people who work as prostitutes;

care, support and treatment of those infected and the protection and support of those caring for them; and

provision of assistance to countries in Australia's immediate region.

The priorities will need to be identified through a process of consultation among health officials and other practitioners, community groups and researchers. The actual research projects selected to be funded will depend on a number of factors including their relevance, the expertise of the researchers, methodological considerations and the importance placed on it by the community.

The components of a research strategy could include research required to:

monitor the spread of the epidemic;

establish appropriate measures to influence and support behaviour change;

improve education and prevention programs to minimise transmission;

improve the technology available for testing for the virus;

develop a vaccine to prevent infection;

develop or identify antiviral drugs for treatment and a cure;

describe the pathogenesis of infection; and

clarify the ethical and legal issues raised by the epidemic.

Education and prevention programs will remain the keystone of any overall strategy to restrain the epidemic over the next decade. The social, epidemiological, economic, legal and political aspects of the epidemic are specific to particular cultures and countries. Australian research in these areas is essential.

Ongoing research is also needed to increase our knowledge of the natural history of infection, to lessen Australia's dependence on technology developed and produced overseas and to reduce the cost of the epidemic to the nation. Appropriate weight needs to be given to fundamental research.

International collaboration is an important contribution that Australia can make to the international response to the epidemic. This will assist Australian experts to evaluate and apply new developments. Participation in international clinical research will give infected Australians early access to experimental treatments.

The balance to be struck between these components will depend on an assessment of which research strategies will in the longer term contribute most to achieving the objectives of a National AIDS Strategy.

7.1.3 Research arrangements

The need to balance competing priorities and to ensure the maximum efficiency of research funding necessitates the national coordination of the research program.

Administration of HIV-related research is undertaken by the Commonwealth AIDS Research Grants Committee (CARG) of the Australian National Council on AIDS. Existing research arrangements include the funding of the two NHMRC Special Units on AIDS research (Section 2.1), the funding of individual projects and commissioned research.

The latter allows research proposals to be sought in areas of perceived need or public concern in fields in which Australia does not have an established research base. Other ways in which such research could be promoted include assigning preference to specified areas in deciding the allocation of research funding, establishing a Special Unit in Social and Educational HIV-related Research, scholarships and convening workshops aimed at encouraging interest among researchers working in related fields. CARG Working Parties also act as a stimulus for research on issues of national concern.

Academic research funded from other sources, research undertaken or commissioned by concerned government or community bodies and research undertaken for other purposes all can contribute to the required knowledge

base. Research may be funded by drug firms and by other firms with a commercial incentive such as the manufacturers of condoms.

Given the extent and urgency of the information requirements of health and other officials and program staff, research funded by governments should provide data which are consistent and comparable to the maximum extent possible and timely access is needed to all research results.

Important data can also be generated from the delivery of services and programs. This can be achieved by requiring that all government funded HIV-related programs contain data collection and analysis and program evaluation components. Projects funded under the Community Grants Program already require an evaluation component. Information gained from regular financial and activity indicator reports could become an important part of a national database.

Possible policy components

- Establish HIV-related research priorities.
- CARG to continue as the major adviser on Commonwealth funded HIV-related research.
- Support research into HIV-related biomedical, epidemiological and social areas.
- Promote research in relevant fields in which Australia does not have an established research base through:
  - commissioned research;
  - assigning funding preference to those areas;
  - establishing a Special Unit in Social and Educational HIV-related Research;
  - scholarships;
  - workshops and working parties.
- Include data collection and program evaluation components in all HIV-related programs funded by governments.

7.2 Monitoring the spread of the epidemic

7.2.1 National epidemiological database requirements

As the incidence of infection increases, the demands on the national epidemiological database will become more complex and extensive. An effort is needed now to increase the effectiveness of the current system and ensure its relevance to planners so that future demands can be met with minimal disruption.

Governments, health officials, and others concerned with the planning, financing and delivery of health and community services need to be able to monitor accurately the course of the epidemic. Data are needed on the reported incidence of HIV infection and AIDS by transmission categories, on annual trends and on mortality and survival rates. Costing studies may require data on the number of diagnosed cases still alive during a nominated year and those who died during a nominated year [Scitovsky and Rice 1987]. The current system provide data on the cumulative number of reported AIDS cases and their mortality by year of diagnosis in a readily available form, but does not publish incidence, mortality or HIV prevalence data.

A system of reporting has been implemented in which laboratories authorised to carry out HIV testing notify the NHMRC Special Unit on AIDS Epidemiology and Clinical Research of the results of all blood tests. All approved laboratories except those in Queensland have agreed to participate fully. Procedures have been devised which should protect the privacy of seropositive people while allowing basic data about sex, age, probable mode of transmission, date of testing, postcode, etc. to be forwarded to the national database. Queensland laboratories have agreed to send data on seropositive results only.

Testing for HIV in accredited laboratories will ensure adequate quality control standards, maintain the required confidentiality, minimise testing costs, and ensure the provision of adequate statistical data.

Every effort needs to be made to minimise the level of duplication in the present coding systems and to collect data on HIV infection in individuals rather than on numbers of tests performed. To achieve this, unique coding systems for notification may need to be devised, that is, systems which, while still ensuring confidentiality, assign a unique identifier to each new notification

The incidence and prevalence of other infectious diseases which may occur as a result of the immune deficiency associated with HIV infection, in particular tuberculosis, should be monitored. An association between

tuberculosis andHIV infection has been demonstrated [Pitchenik et al 1986; Mann et al 1986; CDC 1987c]. This could cause problems for Australia since public health measures against tuberculosis have been relaxed. The incidence of tuberculosis in HIV- positive people needs to be carefully monitored.

Refining the present national data collection and its analysis should be done jointly by the data collectors, data analysts and data users to ensure the maximum usefulness of the collection.

7.2.2 Monitoring AIDS

By the end of 1984, legislation existed in all States and Territories requiring notification of the most advanced stage of HIV infection, the former Category A or AIDS [Appendix 1], to their respective health departments. By agreement with the States and Territories, these data are made available to the NHMRC Special Unit in AIDS Epidemiology and Clinical Research.

A standardised reporting format has been adopted by all States and Territories for the collection of data. For each case reported, data include age, sex, transmission category, place of notification, disease at presentation, date of AIDS diagnosis and date of death where applicable. Notification to the Special Unit is by a code formed by the first two letters of both the family name and the first given name.

This system has been based on the notification of AIDS cases by medical practitioners required by State and Territory laws. Reporting levels have been satisfactory and have been supplemented by information gained by the Special Unit from State and Territory health departments and hospitals. Death certificates received by local health authorities are checked for additional cases. Duplication in reporting is lessened through the cross-checking of duplicate codes with date of birth.

7.2.3 Monitoring HIV infection

The incidence of HIV infection needs to be monitored in the population as a whole and in groups at higher risk. Since HIV infection occurs a varying number of years before the onset of AIDS, data on patterns and spread of HIV infection provide the earliest indication of the extent of the epidemic. These data are essential to increasing the effectiveness of measures designed to limit the spread and in planning for eventual demands on the health and human resource systems.

The difficulties involved in routine HIV testing of the whole population have been discussed in Section 3.3.1. There are also difficulties in testing large representative samples of the population. Without such regular

testing, it will be difficult to measure accurately the prevalence and incidence of HIV infection in the whole population.

Lower bounds on the level of infection in the whole population may be obtained from monitoring data already gathered in Australia on blood donations. Blood donors form a self-selected group biased through exclusion on the basis of risk factors for HIV infection. Data from this group can be used to measure the spread of infection in a group that believes itself to be at low risk.

Data are also collected in Australia from testing people who choose to be tested. Such people include those who practise or have practised behaviour placing them at risk of infection, those who care for infected individuals and people who are concerned about the possibility of being infected.

Assuming members of high risk groups are likely to choose to be tested, the data will overestimate the rate of HIV infection in the population as a whole, but it will provide the upper bound of HIV infection in the whole population.

The range of these data on the upper and lower bounds of HIV infection is very broad and there may be a need for more accuracy through monitoring a cluster of groups which in aggregation may provide a clearer picture of the pattern of HIV infection.

Measuring changes or trends in the level of infection in various subpopulations can provide information for planning and targeting resources, determining the effectiveness of prevention and treatment programs and assessing the development of the epidemic.

For these purposes, it is not necessary to have precise data on prevalence of infection to plan and devise strategies to combat HIV infection. When a high compliance rate can be achieved through voluntary testing, the upper and lower bounds of infection may be established with a greater degree of accuracy. The upper bound can be established by assuming that all those who refused to be tested were infected.

Subpopulations may be chosen as representative of the whole population, from groups considered to be at higher risk or from those likely to spread infection more widely in the community.

Testing particular subpopulations inevitably introduces biases in the data collected which need to be identified and kept as constant as possible over time. Such biases may include age, location, socioeconomic level and whether or not those tested have given their consent.

A number of approaches may be taken when testing for epidemiological purposes:

Compulsory testing. This refers to testing where non-compliance is a criminal offence.

Mandatory testing. This involves testing which isrequired before the performance of some other action, such as donating blood or joining the Australian Defence Force.

Voluntary testing. This category includesroutine testing, where the subject has the option of choosing not to be tested, or testing which is only performed with the specific consent of the subject.

In each of the above cases, test results could either be linked to the individuals being tested, so that people could be informed about their test results, or anonymous, meaning that it would not be possible to link test results with the subject.

Non-voluntary testing for epidemiological purposes

Such testing has been proposed on the grounds that it would ensure a high degree of coverage and would reduce selection biases.

Mandatory testing for subpopulations may introduce its own biases, for instance by discouraging people from presenting themselves to STD or methadone clinics where tests are performed. No measures should be taken which could prejudice the public health objective of preventing transmission.

Compulsory testing is not subject to this criticism, but could be seen as an unwarranted infringement of people's rights, unwarranted in principle or unwarranted at this stage of the epidemic. The WHO Meeting on Criteria for HIV Screening Programs in May 1987 concluded that human rights are best respected by using the least intrusive measures necessary to accomplish specified public health objectives.

Large numbers of people at higher risk, such as the sexually active and intravenous drug users, have already chosen to be tested for their own reasons. Non-voluntary testing for epidemiological purposes should be weighed against the principle of informed consent and the likelihood that it would deter people from contacting health services and public health bodies.

Anonymous testing for epidemiological purposes

Anonymous testing has the advantages of ensuring a high response rate and eliminating self-selection biases. It overcomes the need for confidentiality provisions anddetailed counselling, and so is relatively cheap and can be carried out more extensively than linked testing. It can be used to evaluate the biases arising from consensual testing.

Anonymous testing can be performed with the consent of those tested, as is the case in some epidemiological testing programs in the United States and the United Kingdom, or without consent.

However, anonymous testing without consent has a number of practical and ethical difficulties.

Delinking the results from individuals limits the data's usefulness. Unless testing is performed with consent, the need for demographic data, data on risk factors and history of previous testing will not be met.

Ethical objections have also been raised against anonymous testing. Such testing does not provide people with knowledge about their infection status and its implications, nor allow them to participate actively in deciding on possible courses of action [Gillon 1987]. It cannot be used to assist infected people to change their behaviour or to inform their sexual or drug use contacts.

Non-consensual anonymous testing also overrides the principle of informed consent, discussed in section 2.3. Testing a group without specific consent, even when delinked, involves infringing the privacy of the group as a whole and may have negative consequences for all members of the group. It is also argued that testing individuals without specific consent involves denying them self-determination.

Voluntary testing

While the requirements for counselling and specific consent before testing and for counselling are likely to involve significant resources, there are advantages in adopting a principle of specific consent to HIV testing for epidemiological monitoring. Such testing, when linked to the individual and accompanied by counselling, can be of benefit to the individual as well as of benefit in data collection.

Voluntary testing introduces certain selection biases, which depend on the client group being offered testing, and the extent and quality of pre-test counselling. Nevertheless, biases could be reduced if an education campaign were designed to explain the purpose and importance of a national monitoring system for HIV infection. There are grounds for believing that the response rate would be high.

Appropriate procedures for obtaining consent to prevalence studies, that is, testing for HIV, should be developed and publicised. The procedures may need to vary from group to group. One proposal for obtaining consent is outlined in Gillon [1987].

7.2.4 Monitoring groups at higher risk

Groups at higher risk include male homosexuals, intravenous drug users, STD clinic patients, prisoners, people who work as prostitutes and their clients, and frequent travellers.

Data on infection levels in higher risk groups are required for planning purposes and will indicate whether education and prevention programs within these groups have been effective.

Testing of these groups may be with or without consent. Non-consensual testing would be possible only if members of the groups could be identified. This is not normally feasible, except in the case of prisoners. Non-consensual testing could be introduced at STD clinics and drug treatment programs. However, this could discourage people from attending these centres which would have serious public health consequences.

At present, people at higher risk are tested upon request. Consideration could be given to actively encouraging testing in these groups. This would not only improve epidemiological data, but since such testing occurs with counselling, it could also be beneficial in changing behaviour.

Monitoring these groups may provide data on the potential for the broader spread of the virus into the general community.

7.2.5 Monitoring the whole population

If data are not collected on the whole population or on a representative sample, a group or cluster of groups within the population may be chosen as approximately representative and within which trends in changes in the whole population may be monitored.

Pregnant Women

This group is unbiased in terms of self-selection or exclusion related to risk factors for HIV infection. Blood specimens are routinely collected so tests for the presence of HIV infection could be routinely implemented.

Pregnant women could provide an important group for monitoring trends. Data from these women could be collected with or without consent. Women considering pregnancy or already pregnant may wish to be tested for HIV. They could be asked to consent separately to participation in an anonymous monitoring scheme and, with proper counselling, to being tested for HIV infection.

Data from this group could be supplemented later by data gained from testing women attending family planning clinics and abortion clinics.

Attendees at antenatal or Family Planning Clinics

The ANCA Testing Working Party [ANCA 1988b] considered the consensual testing of people who attend antenatal or Family Planning clinics. These were selected groups which may be representative of populations at low risk of infection. It noted that overseas and South Australian data indicate that the compliance rate would be high. The Working Party did not consider that antenatal clinics would supply sufficient numbers for obtaining meaningful data within a reasonable time frame, and so recommended Family Planning Clinics, which have a larger clientele, as the best choice for prospective consensual sentinel surveys. It estimated the total cost of a two year survey at $2.4m and noted that there would be substantial logistical problems involved with such testing and counselling.

Other possible sample groups

Other groups have been considered for monitoring. These include hospital patients, hospitalised motor vehicle accident victims, work based groups, pathology tests, bodies for autopsies and couples to be married. All of these groups will have biases, at least for sex and age, and often for other factors, which would preclude their generalisation to the population as a whole. For some, especially for frequent travellers, it would be difficult and costly to collect data. Consent for a non-coronial autopsy would have to be gained from an executor, guardian or next of kin.

The ANCA Testing Working Party considered the testing of pathology samples processed by routine hospital laboratories to obtain data on prevalence in the whole population. Assuming a prevalence rate of 0.01 per cent, the Working Party estimated that the cost of anonymous non-consensual testing of approximately 150 000 samples would be $1.4 million. If the estimated prevalence rate was correct, this testing could identify 15 infected blood samples. If performed without consent the number of infected blood samples would be the only information gained. If performed with consent, data could also be gained on demographic variables and risk factors. However, this would significantly increase the costs involved.

Data collected for non-epidemiological purposes

Recruits for the Australian Defence Force are tested, as are some insurance proposers and prisoners. Defence Force recruits are biased by age and sex and are drawn from a small percentage of the population, and applicants are not accepted if they are known to be homosexuals or intravenous drug users. During the recruitment process applicants are told they will be tested for HIV.

Many insurance companies in Australia require testing of anyone proposing to take out a high value insurance policy. Most firms currently set the limit at $400 000 but some have a lower value. Insurance proposers are biased by age, sex, and socioeconomic status. It is estimated that 100 000 tests per year may be undertaken for this purpose within the next two years.

In prisons, there will be different rates of HIV infection depending on the type of prison, attitudes of warders, relations among warders and prisoners and the proportion of longer term prisoners. Past and current intravenous drug users are overrepresented in prison populations. Homosexual activities, homosexual rape and drug use in prison all place prisoners at high risk of infection.

Selection biases in these three groups limit the data's usefulness for monitoring HIV infection in the population as a whole. The coded data should nevertheless be incorporated into the national data system to supplement those collected from other sources.

Specialised data may be required for the monitoring and evaluation of specific programs. Such data will also contribute to understanding of HIV and should be incorporated into a national collection.

7.2.6 Diagnostic assays

Australia must retain a high level of competence in HIV testing technology. To achieve this, adequate facilities must be available to ensure that all necessary testing can be carried out with accuracy, economy, appropriate confidentiality and a minimum of inconvenience. This high standard of technical excellence can only be ensured by continuing support for relevant Australian basic research.

The sensitivity and specificity of the current assays for diagnosis of HIV infection are very high. However, they are largely based on detection of HIV-1 antibodies and assays are needed for the virus itself. Australian investigators are already contributing to this goal and this effort should be maintained to reduce dependence on costly imported kits, and to develop cheaper kits which could also be made available to other countries, particularly in the South East Asian and Pacific regions.

Possible policy components

- Monitor the national epidemiological data collection to ensure that future data needs can be met.
- Educate the population as a whole on the purpose and importance of gathering HIV-related epidemiological data.
- Limit testing to accredited laboratories to ensure the provision of standard data to the national database.
- Determine HIV infection levels in the population as a whole through regular testing of the entire population or of a randomly selected sample of the population.
- Monitor trends in seroprevalence levels by:

  - collecting data on groups at higher risk, in particular people who attend STD clinics and drug programs or people in prison;
  - analysing data gathered for non-epidemiological purposes, for example testing done by the Australian Defence Force and insurance companies;
  - testing a group of people or a cluster of groups which could stand as proxy for the general population.
- Testing to be done:
  - voluntarily;
  - mandatorily;
  - compulsorily.
- Testing to be done:
  - with the results linkable to individuals;
  - anonymously.
  - Continue support to maintain a high standard of technical excellence in diagnostic assays.

7.3 Research for minimising transmission of the virus

Extensive research is needed to assist in the development of education and prevention programs to:

prevent transmission among those at higher risk of infection;

educate groups potentially at higher risk of infection if the virus spreads further beyond the higher risk groups;

educate all Australians on the way the virus is spread and the means to prevent infection; and

develop a vaccine and a cure.

7.3.1 Prevention programs for higher risk groups

More needs to be known about the determinants of, and variations in, sexual and drug taking behaviour, about different groups of understanding of HIV transmission, their attitudes towards infection and their motivation to change or modify their behaviour. Information is needed about social and psychological responses to HIV education, and about lifestyles acceptable to particular groups to minimise the chances of transmission.

Research in this area will need to assist the development of education and prevention programs to establish and reinforce safer behaviour in these groups. A diverse range of research findings and data is required to enable the adequate design, monitoring and evaluation of programs.

Research is needed on sexual behaviour which is epidemiologically related to HIV transmission, including information on sexual initiation and knowledge, sexual orientation and practices, on choices and methods for reducing the risk of HIV transmission and on the social and economic factors which assist or constrain behaviour change. The analysis of data currently held in STD clinics would contribute to knowledge in this area.

The interaction between the individual, culture and society needs to be recognised in research related to sexual transmission of HIV. Individual sexual expression is shaped by a number of factors including the way society constructs masculinity and femininity, peer group norms and social and moral values. This is particularly true for those groups which are at higher risk of transmission since they have a history of social disapproval.

The factors which make women vulnerable to infection need to be identified along with strategies which could lessen this vulnerability. Research related to perinatal or reproductivetransmission is needed, including on the value placed on parenting and on children, and on ways in which knowledge of the risks of sexual or perinatal transmission influence attitudes to sexuality and childbearing.

Research is needed into the psychology of risk taking. Risk reduction in the areas of sexual and drug taking behaviour is important for minimising transmission of the virus.
Research is needed to establish and monitor the adequacy of quality control standards for condom manufacture as well as to determine the factors affecting proper usage.

In the case of intravenous drug users, a number of priority areas can be identified. The first is understanding the social and cultural processes related to initiation into injectible drug use, continuation, modification and quitting. This information would assist designing information packages to discourage individuals from placing themselves at risk of HIV transmission in particular, or of harm in general.

Secondly, the forces which may act against the success of prevention programs aimed at the individual need to be identified. These include the social, economic and historical factors which influence an individual's life, possibly leading to the use of drugs. There is also a need to look at the influence of political processes on HIV-related drug policy, at the influence of the various lobby groups, and the degree to which HIV-related drug policies stand alone or should be understood within wider trends in public health, drug or social policy formation.

7.3.2 National education campaign

The effectiveness of a National Education Strategy will depend on the quality of research about the target audience, the prevalence of risk behaviour and the incentives and barriers to change. However, for some years to come there will be no comfortable assurance of an extensive and proven research base, not only because the results of some longitudinal studies are not yet available but also because the environment is changing.

In the short term, messages and programs may need to be developed on the basis of professional advice and the conclusions that can be drawn from other relevant research and preventive health programs. The risks of this approach can be kept to a minimum by effective program monitoring and evaluation and are outweighed by the consequences, both in human and economic terms, of delay.

Many government campaigns are based on market research which provides guidance on existing knowledge and attitudes, and individual or group

responses to images, messages and concepts. It cannot provide the kind of data required to examine the circumstances surrounding existing behaviours, willingness or resistance to change and individual processes of change. Dependence on the findings of market research can lead to inaccurate and overly optimistic estimations of success or behavioural changes achieved.

Social research can provide in-depth understanding of target audiences. Social research, based as it is in personal contact with a target audience, also provides opportunities for face-to-face education.

Research may take the form of consultation with representatives of the target group in the process of developing specific materials or programs. Such consultation can help ensure that educational materials are appropriately designed, appealing, do not contain inappropriate language or cultural concepts, and focus on the specific concerns and needs of the target group. Research to determine the potential effectiveness of an educational strategy can include piloting the program with the target audience before the form and content are finalised.

7.3.3 Research on a vaccine and a cure

Ultimately, prevention of HIV transmission may be possible through the development of a safe and effective vaccine, or a cure. There are fundamental questions about the nature of the virus, mechanisms of transmission and about the natural history of infection which bear directly on such research.

Given Australia's comparative expertise in virology, immunology and clinical medicine, Australian scientists and clinical investigators have a reasonable chance of making significant contributions to this research. Work related to vaccine development is currently being undertaken in the NHMRC Special Unit for AIDS Virology and at the John Curtin Medical School at the Australian National University.

Possible policy components

- Undertake research into factors underlying risk behaviour and which influence and support behaviour change.
- Undertake educational research based on social research and interaction with target groups.
- Undertake research towards the development of a vaccine and cure.

7.4 Research for the care, support and treatment of infected individuals

The primary requirement for program planning is a comprehensive study of the range of needs, physical, psychological, financial and others, experienced by HIV-infected persons and their carers. The information gained from such studies will provide a means of assessing the comprehensiveness of existing services and programs, identifying any gaps and determining appropriate response levels.

The compassionate and efficient management of health and social care for those infected with HIV, their families, other close contacts and health care workers calls for skills and resources in short supply. While all these new skills have their relevant theoretical disciplinary bases, there are many aspects which can only be learnt in a practical environment dealing with patients in all stages of HIV infection. This process could be assisted by well designed, collaborative research projects.

Much more needs to be known about the natural history of infection with, wherever possible, data being broken down by sex, age and mode of transmission. Studies are needed of infected people in whom the disease has not progressed and those who have learnt to live well with infection. These studies are important to improve knowledge of survival rates and to understand better the mechanisms involved in learning to live with a diagnosis of HIV infection.

The forms of cognitive impairment associated with HIV infection, including AIDS dementia, need to be better understood. Research is needed into the special requirement of caring for HIV-cognitively impaired people. Issues relating to loss, dying and bereavement need to be addressed as part of the psychosocial aspects of service provision to carers as well as to infected individuals. Burnout and high attrition rates in staff and volunteer carers, attributed to high stress levels, have serious implications for health care service provision and need further study.

Clinical trials of promising treatments need to be initiated to meet the need for current information about the range of possible treatments. Trials of new drugs are in general subject to approval by the Department of Community Services and Health, as well as by the ethics committees of institutions where they are to be conducted. The Department's regulatory role is designed to encourage Australian participation in trials of new drugs, as well as to ensure that trial subjects are not exposed to unnecessary risks. Once a complete application to conduct a trial has been received, the trial may proceed if the Department does not notify any objection within 60 working days. Involvement in pre-clinical and early clinical trials would enable researchers access to new drugs early in their development.

Research into nutrition and HIV infection could lead to improvement in patient care, in prognosis and life expectancy. Research is needed to determine whether HIV-related illnesses are amenable to support or alleviation through nutrition.

More data are required on the nutritional status of HIV infected individuals, on the effect of the virus on gastrointestinal function and to determine the link between nutritional status and disease progression. Data are also needed on the risks or benefits of the various nutritional supplements and other complementary or alternative treatments currently being tried by a large number of HIV-infected individuals.

Possible policy components

- Undertake comprehensive research into the physical, psychological and financial needs of people infected with HIV.
- Undertake research in the clinical manifestation and natural history of HIV infection, including HIV-related cognitive impairment.
- Undertake research related to the treatment and management of HIV infection, including chemotherapy and nutrition.

7.5 Research for the education and protection of carers

Research is needed to assist in designing HIV education programs for health care workers and other carers. The diversity of settings in which health care is delivered require occupationally specific programs which should address attitudinal and environmental barriers to appropriate procedures for the care and support of infected persons.

Research is also needed into protective materials and equipment, and the design and implementation of infection control procedures which would encourage their maximum acceptance in the workplace.

Consideration could be given to the initiation of studies at a small number of sites on the applicability and implementation of the accident prevention and infection control guidelines in force in those establishments. These studies could draw upon the methodology developed by Gerberding et al [1987]. Studies could start in units dealing with known HIV-infected patients and in laboratory facilities, and later cover a variety of health care settings including patients being cared for at home.

The risk of occupational transmission in Australia at present is too low to justify any larger scale studies involving the voluntary or compulsory testing of health care staff.

Most care of infected persons is provided by untrained partners, friends and family members who may or may not themselves be supported by volunteer support networks. Research into the needs of and services required by carers themselves should be undertaken.

Possible policy components

- Undertake research into the knowledge and attitudes of those who care for infected people and their educational needs.
- Undertake research into the development of approved protective materials and devices.
- Undertake research into the implementation of infection control procedures to increase their acceptance in the workplace.
- Undertake research into the needs of carers and services required by them.

7.6 Research for costing and resource planning

More comprehensive costing and resource studies of the effects of HIV are needed.

Such studies should indicate the magnitude of uncertainties in variables such as cost components, epidemiological projections and rates of discount, and results should be presented for a range of such parameters.

The Touche Ross study [1987a] identified a framework of cost components underlying their proposed method for determining the total costs of the epidemic (**Figure 5**). The proposed method involved the detailed estimation of each of the components in a base year, such as 1988–89, which could then be used to develop a predictive model over a three to five year period. The total costs of the infection would be the sum of each of the components, except for transfer payments such as income support.

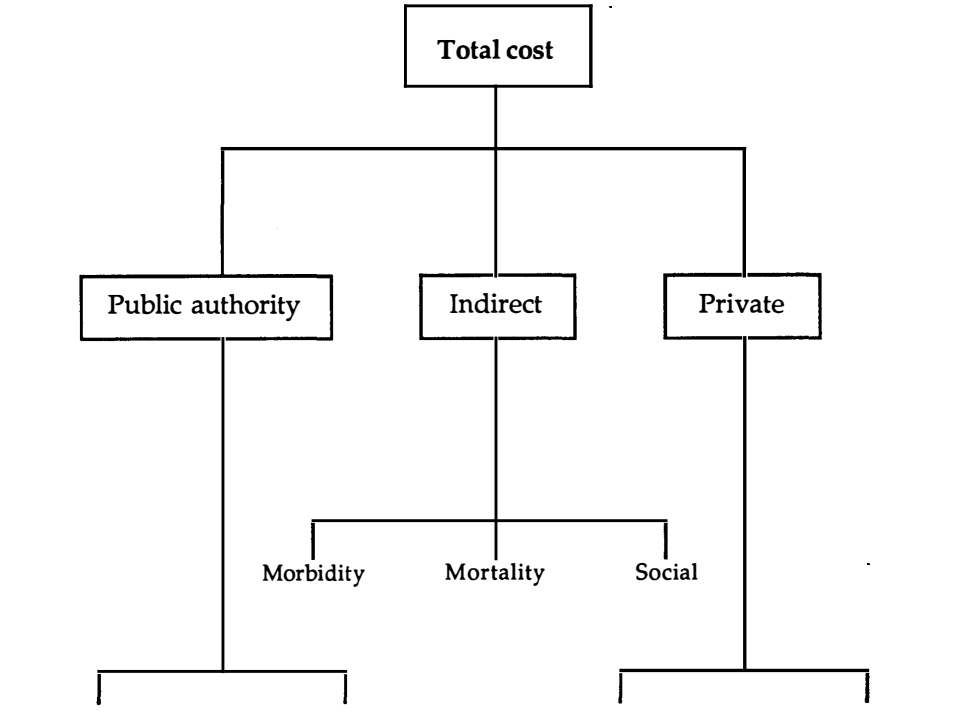
While a full costing in a base year such as 1988–89 will be useful in enabling the total impact of HIV infection at that time to be assessed against other diseases or other issues, the changing nature of HIV, particularly in treatment and care, will make such a costing increasingly irrelevant and difficult to use as base for predictions. Continuously updated data will be required from sources such as hospital records on latest treatment drugs and their effects on inpatient and outpatient costs.

A prevalence approach to costings such as that adopted by Touche Ross, which ascribes costs in a particular year to various components, reflects the requirements of accounting and short-term budgeting and planning by anticipating future calls on resources. This approach to costing requires data on HIV prevalence levels.

However, additional approaches are needed for the development, monitoring and evaluation of intervention strategies. Effective policy making requires that costing be done to indicate where costs are avoidable, and to allow the total costs and benefits of different strategies to be estimated and compared.

Figure 5:

Framework of cost components



General programs

- Administration
- International
- Research
- Education
- Advertising/ public relations
- Prevention programs
- Special programs (AZT)
- Counselling and testing
- Testing specific groups
- Testing blood donations
- Securing blood product
- Training programs
- Insurance costs
- Capital expenditure

Case-related

- Treatment
  - — public hospital
  - — Medicare
  - — Pharmaceutical Benefits
  - — other non-hospital e.g. home nursing
- Support services
  - — homecare
  - — meals-on-wheels
  - — housing
- Social security benefits
- Veterans' Affairs benefits
- Concessions

General programs

- Research
- Education
- Advertising/ public relations
- Prevention programs
- Testing specific groups
- Training programs
- Insurance costs

Case-related

- Treatment
- Sick-pay
- Insurance/ superannuation
- Other income support
- Housing

Source: Touche Ross 1988 a

To do this, costs must be related to the stages of progression to illness following infection, and epidemiological models must be able to produce estimates of trends in incidence of infection and of progression to the various stages of HIV-related illness. In this way, areas where interventions are needed can be identified, and the total avoidable costs in particular groups can be estimated. These costs can be used to determine the relative benefits of different interventions.

Possible policy components

- Determine the magnitude of the various components of costs arising as a result of the epidemic.
- Estimate the relative costs and benefits of different strategies of prevention and treatment.

Monitoring and evaluating a National AIDS Strategy

8.1 Monitoring and evaluating a National AIDS Strategy

The HIV epidemic is one of the major current and future threats to Australia and there is an increasing need to allocate significant resources to prevention and treatment. The economic and social implications of HIV mean that the public policy response at all levels of government should be constructive and effective, and publicly accountable.

All programs and activities need to be adequately monitored and evaluated for their efficiency, effectiveness and impact, and the results used in developing further measures.

The costs to Australia are already significant and will continue to grow. It cannot be anticipated that the Australian community, given current economic circumstances, will agree to substantial additional funding for HIV prevention and treatment unless those activities can be shown to be effective. If there is to be an effective national response, available funding must be directed to those activities which make a positive contribution. Such an approach requires public evaluation. An appropriate infrastructure for design and implementation of the National Strategy is needed, and adequate resources must be provided.

There is a need to develop effective and appropriate evaluation methodologies, particularly in the areas of programs promoting behaviour and attitude change. Evaluation should show whether a particular program is effective, or whether it can or should be modified. The community and individuals affected by HIV have a clear interest in information from such evaluations. Given the financial implications of HIV infection and the necessity for a national response, all possible programs, projects and activities should be included.

There is room for diversity and for innovative programs. However, such programs must be monitored and evaluated for their relevance to specific objectives.

Evaluation should include the concept of accountability: ensuring that available program or activity funds have been spent for the purposes for which they have been allocated, and demonstrating that services provided are efficient and effective.

All program objectives should be clearly stated and, as far as possible, measurable. Standardised activity and performance indicators should be developed, preferably in consultation with grant recipients. A program which is not performing should be modified or abolished. However, it must be recognised that effective policies and programs require flexibility and

responsiveness in administration, and evaluation should take into account implementation times and other constraints.

Successful evaluations, useful for making further decisions, may range from very simple assessments to research oriented and rigorous analysis. It is important that evaluation design is appropriate to the size, scope and cost of the program.

Monitoring, evaluation and accountability require adequate documentation and dissemination of information. Public policy decisions on HIV and the related program activities will rely to a considerable extent on information on costs. However, cost considerations need to be complemented by information on the social and ethical implications of introducing particular programs and activities.

Governments, and HIV-infected people, should be told of the benefits of any new approach. This can be achieved only if there are monitoring and evaluation arrangements established at the national level, and if the States are willing to participate fully in the exchange of information, monitoring and evaluation details on their HIV-related illness programs and projects. Such an approach may also provide a focus for community funded projects.

A monitoring and evaluation body could be established to enable the coordination of monitoring and evaluation of the National Strategy. Its functions could include the formulation of appropriate objectives, targets and indicators, the development of relevant skills and provision of access to these skills by program managers. There are a number of options for an appropriate monitoring and evaluation body.

The Commonwealth Department of Community Services and Health

The Department has detailed knowledge of the HIV epidemic and its program funding, and it has access to the Australian National Council on AIDS. However, the Department would need to develop further close links with State health authorities and a range of agencies providing treatment, care, or services to persons affected, including corrective services and education authorities at State level. This might require a separate structure within the Department.

The Australian Institute of Health

The Institute is an independent statistical research body well placed to undertake or comment in detail on the statistical implications of monitoring and evaluation. However, it would need to demonstrate its capacity for close cooperation with relevant government administrations, the medical profession and all relevant sectors of the community.

The Australian National Council on AIDS (ANCA)

ANCA advises the Commonwealth Minister for Community Services and Health on all aspects of AIDS but it is not structured to undertake a

monitoring and evaluation role. However, it will be important to keep ANCA fully informed of the results of monitoring and evaluation.

Australian Health Ministers' Conference

Through its Advisory Council, the Australian Health Ministers' Conference could establish a broadly based Committee for monitoring and evaluation. It would have the advantage of being closely associated with, and working within, the existing national structures. Such a Committee would need to be given wide terms of reference since many HIV-related programs will be initiated outside health portfolios.

The Premiers' Conference

Since the Premiers' Conference meets infrequently, the difficulties of coordination, reporting and follow-up action could be significant. It may be appropriate for the Premiers' Conference to endorse a Committee established by the Health Ministers' Conference to overcome any barriers to proper monitoring and evaluation and for all State funded programs outside the Federal matched program to be nominated and included in the process.

Possible policy components

- Develop a monitoring and evaluation body within the Commonwealth Department of Community Services and Health or the Australian Institute of Health.
- Establish a monitoring and evaluation committee under the aegis of the Australian Health Ministers' Conference, the Premiers' Conference, or the Australian National Council on AIDS.

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Classification of HIV infection

Classification of HIV infection

In 1982, Australia adopted the definition of AIDS of the Centers for Disease Control (CDC) of the United States. A system unique to Australia for classifying HIV infection was developed and adopted.

The case definition for surveillance of HIV infection was revised in 1986 by the Centres for Disease Control, USA, to include some of the more severe manifestations of HIV infection and to address clinical rather than pathological diagnosis.

The revised classification was adopted for use in Australia from 1 January 1988. Most data collected before 1988 will be classified by the former system.

Former classification used in Australia to 31 December 1987

Category	Description
A	AIDS as defined by a reliably diagnosed disease, at least moderately indicative of an underlying cellular immune deficiency in a person with no known underlying cause of cellular immune deficiency, nor any other cause of reduced resistance reported to be associated with that disease. A positive test for HIV or antibodies to HIV is not required.
B	Cases with either clinical evidence of active infection or defective cell mediated immunity, and a positive test for HIV or antibodies to HIV.
C	Cases with confirmed positive test for HIV or antibodies to HIV, but with no clinical evidence of active infection or deficient cell mediated immunity.

Revised classification, used from 1 January 1988

Group	Description
I	Acute infection. The initial stage occurs one to two weeks after infection. Illness occurs with lymphadenopathy, myalgia, fever and/or rash. Appearance of antibodies to HIV occurs, on average, three weeks to four months after infection with the virus.
II	Asymptomatic infection with positive evidence of antibodies to HIV.
III	Persistent generalised lymphadenopathy.

IV Other diseases. Divided into four subgroups: each may include patients who are minimally symptomatic, as well as patients who are severely ill.

Subgroup A Constitutional disease. Includes one or more of defined levels of fever,diarrhoea and weight loss; and theabsence of concurrent illness orcondition other than HIV infection asexplanation.

Subgroup B Neurologic disease. One or more of the following: dementia, myelopathy or peripheral neuropathy; and the absence of a concurrent illness or condition other than HIV as explanation.

Subgroup C Secondary infectious diseases:

- C-1 Infections listed in definition of AIDS
- C-2 Other secondary infectious diseases.

Subgroup D Secondary cancers. Includes Kaposi's sarcoma, non-Hodgkin's lymphoma or primary lymphoma of the brain.

Subgroup E Other conditions.

AIDS refers to a subset of Group IV infection characterised by a defined opportunistic infection, serious neurological disease or wasting. Not all persons classified under Group IV have AIDS as currently defined.

Resolution WHA40.26 of the Fortieth World Health Assembly

World Health Organization Global Programme on AIDS

Resolution WHA40.26 of the Fortieth World Health Assembly

Global strategy for the prevention and control of AIDS

The Fortieth World Health Assembly,

Having considered the report of the Director-General on WHO's Special Programme on AIDS;

Deeply concerned that this disease, caused by one or more naturally occurring retroviruses of undetermined geographical origin, has assumed pandemic proportions affecting all regions of the world and represents a threat to the attainment of health for all;

Realizing that the transmission of AIDS can be prevented, that information is an essential element of all action for the control of AIDS, and that every individual has a responsibility;

Reiterating that information and education on the modes of transmission, as well as the availability and use of safe blood and blood products, and sterile practices in invasive procedures, are still the only measures available that can limit the further spread of AIDS;

Convinced of the crucial importance of countries' closely integrating their programmes for the prevention and control of AIDS within their health systems based on primary health care;

Impressed by the accelerated response of WHO to this emergency during the past year;

Noting with satisfaction that WHO has invested funds from its regular 1986-1987 budget to deal with this serious public health problem despite current financial constraints;

Grateful to all those whose generous extrabudgetry contributions have made it possible to give the required momentum to WHO's efforts to combat AIDS;

Stressing the need for substantial additional voluntary contributions to permit WHO to fulfil its international directing and coordinating role in this field;

Emphasizing that all contributing countries are protecting the health of their own people no less than that of others, since AIDS knows no geographical boundaries;

Realizing that the worldwide emergency created by AIDS will require urgent and vigorous globally directed action in the development of epidemiological surveillance, the intensification of research in prevention, control, diagnosis and treatment, including social science research, the training of national health workers and other relevant areas of prevention, control and research;

Recognizing that, due to the relatively long incubation period of the disease and the large number of people already infected, the worldwide number of AIDS cases will continue to rise in the next few years irrespective of public health strategies to prevent viral transmission;

1. CONFIRMS that WHO should continue to fulfil its role of directing and coordinating the global, urgent and energetic fight against AIDS;

2. ENDORSES the establishment of a Special Programme on AIDS and stresses its high priority;

3. FURTHER ENDORSES the global strategy and programme structure prepared by WHO to combat AIDS;

4. URGES Member States:

   (1) to establish or strengthen effective programmes to combat AIDS in line with the above-mentioned global strategy and recommendations of the third meeting of participating parties, and to ensure that control is integrated into the existing system based on primary health care, and is based on effective educational and preventive measures to enable each person to protect himself/herself from the disease;

   (2) to cooperate fully with one another in facing this worldwide emergency within the context of the policy of technical cooperation among countries through the adoption of compatible programmes and transfer of appropriate technology;

   (3) to share in full openness with WHO and with other Member States all relevant and reliable information on AIDS and related infections;

5. URGES Member States to make voluntary contributions in cash and kind for the implementation of the global strategy;

6. APPEALS to bilateral and multilateral agencies, as well as nongovernmental and voluntary organizations, to support the worldwide struggle against AIDS in conformity with WHO's global strategy;

7. REQUESTS the regional committees:

   (1) to keep the situation concerning AIDS in the regions under constant review;

   (2) to ensure that regional resources to combat AIDS are used in conformity with the global strategy;

   (3) to report annually to the Director-General on the situation in the regions;

8. REQUESTS the Executive Board to review yearly until further notice the global epidemiological situation concerning AIDS and progress in implementing WHO's global strategy to combat it;

9. REQUESTS the Director-General:

   (1) to ensure that the global strategy to combat AIDS is effectively implemented by the Organization at all levels — country, regional and global — with the aim of containing, progressively reducing and eventually stopping the spread of the infection;

   (2) to assert WHO's international directing and coordinating role in support of national AIDS programmes;

   (3) to support national AIDS prevention and control programmes, keeping due balance with other health programmes and ensuring adequate coordination and cooperation between the governments concerned, WHO and other external partners;

   (4) to continue to develop effective strategies to prevent the transmission of AIDS, including social and behavioural research and advocacy of the role of women in preventing transmission;

   (5) to reinforce the Organization's support to Member States in designing or strengthening, implementing, monitoring and evaluating national programmmes for AIDS prevention and control;

(6) to issue guidance on the prevention and control of AIDS on a continuing basis as new information comes to light and the Special Programme evolves;

(7) to continue to seek extrabudgetary funds to implement the global AIDS strategy;

(8) to establish a Special Account for AIDS in the Voluntary Fund for Health Promotion;

(9) to report on the matter to the Executive Board and to the Health Assembly annually.

*Hbk Res., Vol III(1st ed.), 1.16.13 (Twelfth plenary meeting, 15 May 1987 — Committee A, third report)

Resolution WHA41.24 of the Forty-first World Health Assembly

World Health Organization Global Programme on AIDS

WHO against AIDS discrimination

The Forty-first World Health Assembly adopted resolution WHA41.24 in Geneva on 13 May 1988.

Avoidance of discrimination in relation to HIV-infected people and people with AIDS

The Forty-first World Health Assembly,

Recalling resolution WHA40.26 on the global strategy for the prevention and control of AIDS, Economic and Social Council resolution 1987/75, and United Nations General Assembly resolution 42/8 on the prevention and control of AIDS;

Endorsing the London Declaration on AIDS Prevention unanimously adopted on 28 January 1988 by the World Summit of Ministers of Health on Programmes for AIDS Prevention;

Recognizing that AIDS is a global problem which poses a serious threat to humanity, and that urgent and worldwide action is required to implement WHO's global strategy to combat it;

Acknowledging with deep appreciation the work of WHO, through the Global Programme on AIDS, in directing and coordinating the global strategy;

Noting the medical, ethical, legal, socioeconomic, cultural and psychological implications of AIDS prevention and control programmes;

Recognizing the responsibility of Member States to safeguard the health of everyone and to control the spread of HIV infection through their national policies and programmes, taking into account their epidemiological situation, and in conformity with the global strategy;

Bearing in mind the responsibility of individuals not to put themselves or others at risk of infection with HIV;

Strongly convinced that respect for the human rights and dignity of HIV-infected people and people with AIDS, and of members of population groups, is vital to the success of national AIDS prevention and control programmes and of the global strategy;

1. URGES Member States, particularly in devising and carrying out national programmes for the prevention and control of HIV infection and AIDS:

   (1) to foster a spirit of understanding and compassion for HIV-infected people and people with AIDS through information, education and social support programmes;

   (2) to protect the human rights and dignity of HIV-infected people and people with AIDS, and of members of population groups, and to avoid discriminatory action against and stigmatization of them in the provision of services, employment and travel;

   (3) to ensure the confidentiality of HIV testing and to promote the availability of confidential counselling and other support services to HIV-infected people and people with AIDS;

   (4) to include in any reports to WHO on national AIDS strategies information on measures being taken to protect the human rights and dignity of HIV-infected people and people with AIDS;

2. CALLS ON all governmental, nongovernmental and international organizations and voluntary bodies engaged in AIDS control programmes to ensure that their programmes take fully into account the health needs of all people as well as the health needs and dignity of HIV-infected people and people with AIDS;

3. REQUESTS the Director-General:

   (1) to take all measures necessary to advocate the need to protect the human rights and dignity of HIV-infected people and people with AIDS, and of members of population groups;

   (2) to collaborate with all relevant governmental, nongovernmental and international organizations and voluntary bodies in emphasizing the importance to the global strategy for the prevention and control of AIDS of avoiding discrimination against HIV-infected people and people with AIDS;

   (3) to stress to Member States and to all others concerned the dangers to the health of everyone of discriminatory action against and stigmatization of HIV-infected people and people with AIDS, and members of population groups, by

continuing to provide accurate information on AIDS and guidance on its prevention and control;

(4) to report annually to the Health Assembly through the Executive Board on the implementation of this resolution.

WHO/GPA/NF/88.2

Index

Aboriginal and Torres Strait Islander people
preventive education for, 106, 137-8
training of health workers, 171, 172
treatment and care needs of, 171
abortion, 98, 172
abstinence
from intravenous drug use, 103
from sexual activity, 96, 103
accident prevention procedures
see occupational health and safety
accommodation, 197
see also housing
ACTU Discrimination Policy, 152
acupuncture, 153
acute illness, 60, 61-2, 63-6 passim
Adelaide-based studies, 71
adolescents, 102
preventive education for, 141-6 passim
advertising for prevention of transmission amongst young people, 143
advertising and public relations costs, 76, 79, 80
Africa, 8-9
blood borne transmission, 40
epidemiology, 50, 51
male to female ratio of incidence, 46
seroprevalence, 39-41, 226
seroconversion rates for genital ulceration, 51
transmission modes in, 40-1
AIDS buses, 132
AIDS Councils, 87-8
AIDS Dementia Complex; 62-4
planning for case management and treatment 192-3, 194-5
research into, 247
AIDS hotline, 135
AIDS Information for Travellers, 119, 167
AIDS units in public hospitals, 187
see also hospital based care
albumin, 65
alcohol, 61, 69-70, 72, 129
Alcohol and Drug Information Service, 135
AL721 , 169
America, 50
see also North America; South America; United States of
amphetamines, 98, 129
anal gonorrhoea, 67
anal intercourse, 8, 39, 40, 68
ANCA *see* Australian National Council on AIDS
Ankali Project, 165-6
antenatal clinics, testing of women at, 113, 240-1
antibodies, detectability of, 62
anxiety, 65
apathy, 63
appetite loss, 61, 64
arms and legs peripheral nerve inflammation, 84
artificial insemination, 61-2, 56
Asia
epidemiology, 41
seroprevalence levels amongst prostitutes, 118
asymptomatic infection, 62
Australian Capital Territory, 81
incidence, 46-7
see also Canberra
Australian Council of Trade Unions
workplace policies, 151-2, 159
Australian Defence Force
testing in, 241
Australian Federation of AIDS Organisations, 87
Australian Health Ministers' Conference, 256
Australian Institute of Health, 255, 256
Australian International Development Assistance Bureau, 227-9
Australian National Council on AIDS, 87, 255-6
Australian Prostitutes Collective
preventive programs run by, 68, 148
Australian Standards Association
condoms, 121-2
autopsies
occupational health and safety for, 214
AZT *see* Zidovudine
babies *see* children; perinatal transmission
barriers to prevention of transmission, 100-1
see also legislation
basal cell carcinoma, 65
Beat Box, 143
bed-day costs, 74-5
behaviour, research into, 244-5
behavioural change in response to epidemic, 67-72, 91-2, 101, 111
behavioural differences, role of in determining progress to severe illness, 61
behaviours transmitting infection, 39-41
bereavement, 161
bereavement counselling, 166
birth *see* perinatal transmission
bisexuals, 97
and behaviour change, 67-72 passim
prevention strategies for, 128-31
biting, 28-9
Blah Blah Blah, 143
bleach, 133
blindness, 64
blood, seropositivity in, 58, 121
blood borne transmission, 40-1, 43, 45-6, 50, 54-9

see also blood transfusion; haemophilia; intravenous drug use; needle and syringe sharing; needlestick; organ transplantation
blood products
screening, 149
transmission, 40-1, 45-6, 55-6
blood screening, 56, 76, 78, 79, 80, 108, 109, 149-50, 158
see also testing; Touche Ross
blood testing
see testing
blood transfusion and blood products recipients
preventive strategies for, 149-50
support services for, 149-50
see also haemophilia
blood transfusion service costs, 78, 80
body fluids exposure, 56-9
see also occupational injuries
bone marrow impairment, 65
breast milk, seropositivity in, 58
see also perinatal transmission
broadcasting
programs for preventive education, 143
standards for educative material, 125
see also media
Canberra
sterile drug equipment availability, 132
cancers, 61, 63, 65
care, support and treatment of infected people, 161-207
research into, 247-8
see also treatment
care and safety issues
children, 174-6
employees, 176-9
see also occupational health and safety
care and support services
see community based programs; gay community; Home and Community Care Program; support services; voluntary workers
carers of infected people, 161-2, 175, 219-20
research into education and protection of 249
rights and responsibilities of, 221-2
see also health care workers; occupational health and safety; voluntary workers
Carer's Pension, 180
CAPG *see* Commonwealth AIDS Research Grants Committee
Caribbean
epidemiology, 50
seroprevalence in, 40-1, 226
case management, 192-3, 193-203 passim
case related costs, 73-85 passim
see also Touche Ross
censorship standards for educative information, 125
central nervous system, lymphoma of, 63-4
see also neurological
chancroid, 51
chemotherapeutic treatment, 168-70, 248
child bearing
prevention of perinatal transmission, 98-9, 136-7
see also perinatal transmission
child care needs of infected women, 172
children *see* day care centres; pre-schools; schools; young people
children, infected, 41
clinical manifestations in, 63, 65-6
policy development for rights and needs of 174-6
see also biting; parenteral exposure; perinatal transmission; United States of America
children under government care
preventive education for, 141-3
civil rights
of infected people, 174-191
legal provision for, 204-6
classification convention for reporting cases, 83, 45-6
see also transmission modes
classification system for HIV infection, 235-6
see also Appendix 1
clinical manifestations, 31-7
clinical treatment *see* hospital based care
cocaine, 98, 129
code of practice for superannuation, 187, 188
Code of Practice on AIDS and life insurance, 184, 185, 186
cognitive impairment, 63-4
research into, 248
coma, 63
Commonwealth AIDS Research Grants Committee, 233-4
Commonwealth funding to States and Territories 75, 76, 77, 187
Commonwealth Government expenditure 75-85 passim
see also Department of Community Services and Health; Medicare
Commonwealth Scientific and Industrial Research Organisation, 167, 169
community based care and services, 84-5, 161-2, 164-7, 200-3
liaison with hospital special units, 196
planning for, 192-203 passim
role of in caring for infected children and their families, 175
role of general medical practitioner 195-6

see also Home and Community Care Program; program related costs; voluntary workers; youth workers
community groups, role of, 200-1
see also volunteers
community nursing services, 88
compensation, 158, 189-91
condom distribution, 129-30, 132, 142, 148
in prisons, 139, 140
condom standards and availability, 120-2, 129-30, 132, 158
condom use, 50, 52-3, 68-9, 70, 71, 95-6, 103, 143, 147-8
legislative barriers to, 69, 72
confidentiality, 92, 109, 114-15, 218
ACTU policy, 151-2
legal provision for, 204-6
of health and social security records, 182
policy issues, 174, 175
in life insurance matters, 185
in the workplace, 178
confusion, 63-4
consent
for contact tracing, 114-5
for treatment, 168
consent and counselling procedures for testing, 93, 109-10
consumer protection for non-approved treatments, 170
contact tracing, 114-15
continuum of care, 192-3
see also case management
contraceptives see condoms
convulsions, 64, 66
coordination loss, 63, 64
costing
research into, 235, 250-2
methodologies, 73-5, 82-3
see also Touche Ross
costing studies, 73-85 passim
costs, indirect, 78, 82
see also human resource implications
costs, private, 74
Council of Social Welfare Ministers, 175
counsellers, trained
necessity and policies for, 165-6
counselling, 71, 91, 104, 105, 108, 109-18, 165-7, 192, 193-4
expenditure on, 51, 55
for loss and bereavement, 161, 166
needs of people with haemophilia, 166, 172
needs of infected needle and syringe sharing drug users, 171
needs of infected people, their families and friends, 161-3, 165
needs of prisoners, 171-2
needs of women, 98-9, 156
self-help groups, 166-7
counselling coordinators, 193-4
see also National AIDS Program; program related costs; Touche Ross
crisis accommodation, 197
Cryptococcus neoformans, 64
CSIRO *see* Commonwealth Scientific and Industrial Research Organisation
cytomegalovirus, 52, 64
data collection, 41-9 passim, 235-43 passim
day care centres
as an adjunct to institutional and home care services, 197
day care centres, children's
development of guidelines for care, safety and confidentiality in, 174-6
death
policies for handling and transportation of infected bodies, 120
see also autopsies; bereavement
decriminalisation of non-medically prescribed drugs, 134
see also legislation
defence force *see* Australian Defence Force
dementia *see* AIDS Dementia
Department of Community Services and Health, 75-80, 168, 247, 255, 256
and international assistance, 227-8, 229
policies concerning immigration, 117
Department of Immigration, Local Government and Ethnic Affairs
screening of immigrants, 117
Department of Social Security, 180, 181
depression, 61, 65, 71-2, 162
dermatitis, 62
development assistance
see international cooperation
dextran sulphate, 169
diagnostic assays, 242-3
diarrhoea, 61, 62, 64, 167
diet, 161, 167
dietary supplementation, 167
digital contact, 52
disability allowance, 181
disabled people, preventive education for, 141-3 passim
discrimination, 206-7, 224
against children, 174-6
by insurers, 184-5, 186
legislation to counter, 176, 179
in the workplace, 151-2, 176-9
see also civil rights
drug equipment, legislation for use or sale, 95-6
Drug Offensive media campaigns, 104
drug prevention programs, 135-6

drug substitution programs, 106, 133
see also methadone
drug taking behaviour
research into, 245
drug treatment services, 133, 134, 136-7
drug treatment agencies, role of, 133, 134
drug use, recreational, 68
see also alcohol
drug use transmission prevention, 95-6, 97-8, 131-48 passim
drug users
epidemiology, 40
see also intravenous drug use
drugs, research, development and production of, 168-70, 232, 246, 247
ear piercing, 153
Eastern Europe
epidemiology, 41
economic costs, 73-85 passim
education for prevention, 84, 89, 90, 91, 95-107, 131, 133, 135-48 passim, 161-3, 232-3
for people in closed institutions, 141-3
decontamination of drug equipment, 133
for intravenous drug users, 131-3, 134-6, 138-48 passim
for infected people, 161-3
for immigrants, 115, 117-18
for people in prisons, 138-41
for priority groups, 128-50
research into, 244-6
in schools, 143-4
in tertiary institutions, 144-5
for travellers, 115-17, 118-20, 156-7
in youth training centres, 145-6
in the workplace, 161, 155-6
see also advertising; occupational health and safety; perinatal transmission; preventive programs; women
education costs and expenditure, 73-85 passim
see also program related costs; Touche Ross
education and training
access to by infected people, 176
employees, infected, 176-9
see also education; occupational health and safety, overseas postings; workers compensation; workplace
encephalitis, 61, 63
encephalopathy in children, 66
epidemiology, 39-51, 235-43
global, 39-41, 50-2
monitoring, 235-6
Europe
epidemiology, 40-1, 55
prevalence rates for intravenous drug users, 54, 118-19
expenditure, government, 73-85 passim
see also Commonwealth; Medicare; Touche Ross
Fairfield Hospital, Victoria, 74, 88
family members, relations with, 65, 161
fatigue, 62
see also lethargy; malaise
fear of dying, 65
fear of transmission, 59
fever, 61, 62, 65
finance, housing, 183-4
first aid protocol, 154
France
occupational injuries, 56-7
funding of health services
see Commonwealth; government; Medicare
funerals
handling and transportation of human remains, 120
fungi, 63, 64
gastrointestinal system impairment, 61, 64, 65
Gay and Married Men's Association, 130
gay community organisations
role of, 67, 70, 72, 128, 161
gay media, 67
genital ulceration, 51
gestation *see* perinatal transmission
global prevalence, 39-41, 50-2, 118-19
see also international cooperation; World Health Organization
gonorrhoea, 67, 69
government expenditure, 73-85 passim
see also Commonwealth; Department of Community Services and Health; Medicare
guardianship schemes, 202
Haemophilia Foundation of Australia, 149, 150
proposals for compensation, 189-90
haemophiia, 149-50
incidence, 40
prevalence, 149
preventive education for people with, 189-50
treatment needs of people with, 172-3
headaches, 61, 64
health and community care and services planning for, 192-203
see also public health
health and community workers, 66
see carers; community; occupational health and safety; voluntary carers; workers
health and safety at work, 151-9
see also occupational health and safety
health benefits, 180-2

health insurance, 186-7
community rating principle, 186-7
health services
for infected people, 161-91 passim
respective government responsibilities, 198
see also case management; treatment
health treatment
see treatment
hepatitis 8, 52, 55, 56, 151, 154
and needlestick injuries, 56-7
heroin, 98, 129
see also methadone
herpes simplex, 51, 52, 64
heterosexual transmission, 43, 50-3, 67-72, passim
incidence, 40-1, 45, 46
prevalence, 51
HIV encephalopathy, 63-4
see also encephalitis
HIV-related wasting syndrome, 63
Home and Community Care Program, 164, 181, 198
home based hospice care, 196-7
home based treatment, 84, 194, 195
as an adjunct to hospital care, 197
liaison with hospital special units, 196
see also community based care; housing
home ownership assistance, 183-4
home purchase assistance scheme, 183
homosexual transmission, 43, 45, 46, 49, 50, 51, 67-72 passim
incidence, 40
incidence in Sydney and Melbourne, 48-9
between women, 51
legislative barriers to safer behaviour, 69
prevention strategies for, 128-31
hospices, 197
see also palliative care
hospital based care
case management, 192-3, 196-6
clinical research into treatment in, 196
day care centres and home care services as an adjunct to, 195, 196
for people with neurological impairment 194
separate specialist hospitals, 196-7
special treatment units, 196, 196, 197
hospital based treatment costs, 74-5
hospitalisation, 62, 63, 65
hospitals, transmission in, 57
housekeeping needs of infected women, 172
housing, 182-4
see also accommodation
housing finance, 183-4
hugging, 58
human resource implications, 73-85 passim
human resource planning, 198-9
human retrovirus see HIV
human tissues transmission, 55-6
see also organ transplantation
illness, acute, 60, 61-2, 63-6 passim
illnesses, 60-6
immigrants, screening of, 115, 117-18, 119
see also refugees
immune system, 60-6 passim
immunisation, 123
see also vaccine
immuno-suppression, 51-2
immunodeficiency, 60-6 passim
immunology, 246
see also National Health and Medical Research Council
incidence, 39-51
annual, by age, 46-7
annual incidence and mortality, 42-4
by mode of transmission, 43, 45-6
by States, Territories and sex, 43, 47
male to female ratio, 46
projected, 48-9
see also prevalence
incidence costings, 73
income maintenance, 74, 93, 180-2
see also insurance; social security; superannuation; Veteran's Affairs benefits
incontinence, 63
industrial relations policy issues, 176-9
infants *see* children
infection, cases of
see incidence; prevalence
Infection Control Guidelines, 213
see also occupational health and safety
infection elimination
see behaviour change
infection patterns and trends
see epidemiology
injections *see* intravenous drug use; needle and syringe sharing
inpatient psychiatric units, 194
see also hospital based care
insect transmission, 58
insemination, artificial
and transmission, 51-2, 56
institutions, people in
treatment and care needs of, 171-2
preventive education for, 141-3
segregation of, 142
see also prisons
insurance
testing for antibodies, 241
see also health insurance
insurance, complaints regarding, 185, 186
insurance, life, 184-6
Code of Practice on AIDS, 185, 186
policy issues, 184-6

insurance premium payments assistance, 186
Intergovernmental Committee on AIDS, 87
international cooperation, 224-9
intra-uterine transmission
see perinatal transmission
intravenous drug use, 43, 45, 68, 70, 129
incidence, 40, 55
legislative barriers to safer behaviour, 69, 70, 72, 131
overseas incidence, 54-5
preventive strategies for transmission, 97-8, 131-3, 134-48 passim
in prisons, 138-41, 242
and prostitution, 49, 55
research into, 245
treatment, services and programs, 54, 133, 134
see also needle and syringe sharing; prisons
Invalid Pension, 180
irritability, 61
Islander people *see* Aboriginal and Torres Strait Islander people
isolation, feelings of, 65, 72, 162
Isoprinosine, 169
Italy, occupational injuries in, 56-7
Jackson Report, 227
Jarrah House, 136
John Curtin Medical School, 246
joint pains, 61
Kaposi's sarcoma, 63, 64, 65
kissing, 52, 58
laboratories, diagnostic, 88
labour force planning, 198-9
Langton Clinic studies, 70
learning difficulties, 63
leg coordination impairment, 63, 64
legal issues in health care, 221-2
legal protection for infected people, 204-6
legal system, education for workers in, 127
legislation, 91-2, 95, 96
need for amendment, 96-8, 134
to counter discrimination, 176, 179
as an impediment to public health objectives, 69, 72, 98, 125, 129, 131, 148
role of in minimising transmission, 124
for notification of terminal stage of infection, 236
for notification of infected individuals, 42
lethargy, 61
life insurance
see insurance
Life Insurance Federation of Australia, 185
love, ideology of, as a risk factor, 70, 101
lubricants for condoms, 50, 52, 121
lung impairment, 63, 65
lymph glands, 61, 62, 65
lymphocytic interstitial pneumonitis, 63
lymphoma, 62, 64, 65
malaise, 61
mandatory testing, 111-12, 238
overseas, 157
married men, 97, 130-31
see also bisexual men
masturbation, 52
media, role of in influencing behaviour change, 67, 104-5, 119, 130, 143, 162-3
Medicare, 74, 77, 181, 187
see also Touche Ross
Medicare Agreements, 75, 77
melanomas, malignant, 65
Melbourne, 67
incidence, 49
role of prostitutes' collectives in behaviour change, 67, 148
Melbourne-based studies, 60, 68
memory loss, 63
see also neurological impairment
men
preventive strategies for, 97, 128-31
see also bisexual; heterosexual; homosexual; needle and syringe sharing; prostitutes
meningitis, 61, 62, 64, 65
mental state impairment, 65
see also neurological impairment
methadone programs, 133, 171
Middle East
epidemiology, 41
migration *see* immigration; refugees
Ministerial Council on Drug Strategies, 135
mobility allowance, 181
monitoring AIDS, 236
monitoring HIV infection, 236-9
monitoring risk groups, 248
monitoring the general population, 280
monogamy, 96, 103
morbidity and mortality costs, 78, 82
mortality rates, 42-5
mortgage relief schemes, 183
motor function impairment, 63, 64, 66
mucous membranes, transmission through, 56-7
muscle pains, 61
National Advisory Committee on AIDS
insurance policy, 184-5
working party on guardianship and volunteers, 202
National AIDS Counsellors' Association, 193
National AIDS Program, 76
National AIDS Strategy, 87-93, 231-52, 254-6
National AIDS Task Force
Infection Control Guidelines, 213
National Education Strategy, 101-7, 245-6

National Health and Medical Research Council
data collection, 42-9
Special Unit for AIDS Virology, 88, 169
Special Unit in AIDS Epidemiology and Clinical Research, 88, 235-6
National HIV Reference Laboratory, 88
national policy, need for, 87-8
see also policy
natural history of infection, 60-1
nausea, 61, 64
needle and equipment sharing drug use
research into, 43, 45, 54-5, 59, 68, 69, 70
needle and syringe distribution and exchange schemes, 54, 83, 98, 132, 136-7
decontamination of equipment, 133
in institutions, 142
in prisons, 139, 140-2
needle and syringe sharing drug users
incidence, 45-6, 129
preventive strategies for transmission, 95, 97-8, 131-48 passim
treatment needs of, 171
see also intravenous drug use
needlestick injuries, accidental, 56-7
neo-natal death
see perinatal
nervous system impairment, 61-6
see also neurological impairment
Netherlands
incidence rate reduction through needle, exchange etc. and treatment programs 54
neurological impairment, 63-4, 66
planning for case management and treatment of192-3, 194-5
see also nervous system
New South Wales, 81, 139, 148, 153, 168
incidence, 46-7
see also Sydney
New South Wales Privacy Committee, 110
New York City, 116
prevalence in intravenous drug users and children, 55
New Zealand
epidemiology, 40
non-specific pneumonitis, 63
nonoxynol-9, 52-3
North America
epidemiology, 40
prevalence, 39
Northern Territory, 81, 139
incidence, 46-7
notification of partners, 115, 213
nutrition, 61, 161, 167-8, 170
research into, 248
nutritional depletion, 64
occupational health and safety, 56-7, 93, 151-9, 174-9
ACTU policy on, 151-2
research into, 249
occupational injuries, 56-7, 153-4
occupational transmission, 153-4
opportunistic infections, 60-6 passim
oral drug taking, as a preventive alternative, 133
oral sex, 52
organ donor testing, 56, 111
organ transplantation, 46
orogenital intercourse *see* oral sex
overseas travel and postings, 156-9, 225
Pacific region
epidemiology, 41
seroprevalence levels amongst prostitutes, 118
paediatric patients, 65-6
see also perinatal
palliative care, 196
Papua New Guinea, seroprevalence in, 226
parenteral exposure, 56-7
Parliamentary Liaison Group, 87
patterns of infection *see* epidemiology
percutaneous exposure, 56-7
perinatal transmission, 40, 41, 46, 50, 52, 53-4, 55, 58, 95
prevention and treatment programs for women 98-9, 136-7
testing to minimise, 113
see also pregnancy
peripheral nerve inflammation, 61, 64
personality
behaviour changes, 65
personnel issues, HIV related, 176-9
see also employees; work
Perth
role of prostitutes collectives in prevention, 67
Pharmaceutical Benefits Scheme, 74, 77, 169
pharmaceutical services, 180-2
planning for health and community services, 192-203
plasma protein fraction, 55
Pneumocystis carinii, 63
pneumonia, 63
pneumonia in children, 65-6
policy development, 87-8
for infected adults, 161-73
for infected children, 174-6
national, 89-93
research required for, 231-52 passim
for the workplace, 151-9
postnatal transmission
see perinatal transmission
poverty, individual and State as a factor in transmission, 41

pre-schools
development of guidelines for care, safety and confidentiality in, 174-6
pregnancy, 98-9
prevention of perinatal transmission, 136-7
testing of women at antenatal clinics, 113, 240-1
see also perinatal transmission
Premiers' Conference, 256
prevalence, 39-51
see also global prevalence; incidence
prevalence costings, 73-85 passim
prevention of transmission, 77, 83, 91-3, 95-9
for people in institutions, 141-3
for people in prisons, 138-41
strategies for priority groups, 128-150
research for, 244-52
preventive education, 84, 95-9, 100-7
preventive programs, 73-85 passim
see also advertising; blood screening; education; program related costs; Touche Ross
primary care provision
see general practitioners; hospital based care
Prince Henry Hospital, 74
prisons, people in
data collection in, 242
prevention strategies for, 134, 138-41
segregation of, 139-40, 171
testing of, 139, 141
treatment needs of, 171, 172
prevention of transmission in, 113
privacy
see confidentiality
problem-solving difficulties, 63, 64
productivity costs, 78, 82-3
see also human resource implications
program expenditure
for States and Territories, 81
see also costing
program planning, 162, 164, 192-203 passim, 231-52 passim
program related costs, 73-85 passim
see also human resource implications; National AIDS Program; Touche Ross
projections of incidence, 48-9
prostitutes, 51, 68
incidence, 49
preventive education for, 129, 147-8
prevalence overseas, 9
prostitutes collectives
preventive programs run by, 67, 68-9, 148
prostitution
heroin use, 70
international epidemiology, 41, 51, 118
and intravenous drug use, 55
legislative barriers to safer behaviour, 69, 96-7, 148
protective work policies and practices
see occupational health and safety
psoriasis, 62
psychiatric manifestations, 65
psychiatric patients
preventive education for, 141-3
psychiatrists, role of, 194-5
psychological aspects of infection
planning for case management and treatment 192-3, 194-5
psychological manifestations, 65-6
psychologists, role of, 194-5
public health measures, 95-123
see also public policy
public health objectives, 89, 90-222 passim
public hospital system, additional costs to
see government; Medicare Agreements
public hospitals, AIDS units in, 187
public policy for prevention
priorities for, 128-50
see also public health
public relations *see* advertising
Queensland, 81, 129, 139, 148, 153, 189
incidence, 46-7
mortality rates, 43
rashes, 61
razor sharing, 154
recreational drugs, role of in sexual behaviour, 69-70
Red Cross, 149
refugees, screening of, 115, 118, 119
remote area allowance, 181
rental housing, public, 183
reporting of cases
see data collection; incidence
research, 88, 231-52 passim
care and support of carers, 249
coordination, 232-4
costing and resource planning, 250-2
costs, 74, 80
expenditure, 76, 79
dissemination of findings of, 235-6
drug development, 232, 246
education and protection of carers, 249
into monitoring the general population, 41-2, 240-2
into monitoring groups at higher risk, 240
into monitoring HIV and AIDS, 236-9
see also data collection; National Health and Medical Research Council; World Health Organization
research requirements, 167, 231-9
respiratory disease, 63
rest as a cofactor to immunodeficiency, 61
retina cells, 61
retina infection, 64

retrovirus infection, 49
see also HIV
rights, civil, of infected people, 174-91
rights of individuals
legal provision for, 204-6
risk groups, 102, 240
risky behaviours, 50-3, 54, 55, 56-7, 67-72 passim, 101, 103
see also intravenous drug use; needle and syringe sharing
role models, use of for behaviour change, 106
rubber condoms, 50, 52-3
rural areas, programs and trained personnel in, 84, 162
safer sexual practices, 50, 52-3, 67-72, 96-7, 103
safety and care issues
children, 174-6
employees, 176-9
St Vincent's Hospital, Victoria, 74
saliva, 58
schools
development of guidelines for care, safety and confidentiality in, 174-6
screening of international travellers and immigrants, 115-17, 117-18
see also refugees; testing
segregation
of seropositive prisoners, 139-40
of other groups, 171
self-help and support groups, 166-7
semen
exposure to as cofactor to immunodeficiency, 61
seropositivity of, 51, 58, 121
see also artificial insemination
septicaemia, 65
seroconversion, rate of in seronegative men, 68
seroconversion rates amongst prostitutes, 148
serological surveys, 39
seroprevalence testing, 108-139
see also testing
services, planning for, 192-8 passim
see also treatment
sexual and other behaviour research, 244-6
sexual behaviour, 67-72, 97
and transmission risk, 40
awareness of dangers posed by, 67-8
sexual orientation
denial of as an impediment to safer sex, 96-7
sexual transmission, 40-1, 43, 45-6, 48, 49, 50, 58
see also epidemiology; heterosexual; homosexual; prisons; prostitution
sexual transmission prevention, 96-7
sexually transmitted disease, 40, 48, 51, 61, 67, 69, 109-10
contact tracing, 114-15
see also syphilis
sexually transmitted diseases clinics, 112, 114, 240, 243, 244
short-term memory difficulties, 63
Sickness Benefit, 180
skin infections
bacterial, fungal and viral, 62
skin lesions, 64, 65
skin lesions, transmission through, 56-7
see also sexually transmitted disease; ulceration
smoking of drugs as a preventive alternative, 133
snorting of drugs as a preventive alternative, 133
social responsibility *see* prevention
social security, 180-2
see also income maintenance
Social Security Review, 181
South America
epidemiology, 40
seroprevalence in, 226
South Australia, 81, 139, 148
incidence, 46-7
see also Adelaide
South Australian Children's Interest Bureau, 175
special units
see hospital based care
speech and thought impairment, 63
spermicide, 52-3
spinal cord impairment, 61, 64
State wards *see* children under government care
statistics collection, 41-50
see also data collection
sterile equipment
legislative barriers to use of, 69, 72, 131
preventive programs, 131-7
stigma, 194
Streetwize comics, 145
stress, 61
superannuation, 187-9
support for carers
see occupational health and safety
support services
see community care and services; counselling
support services for carers, family and friends of infected people, 161-2
supported accommodation, 197
survival rates *see* mortality rates
sweats, 61
Sydney, 39, 48, 67, 89
Ankali Project, 165-6

incidence, 48, 49
prevalence in intravenous drug users, 55
role of prostitutes collectives in behaviour change, 67, 148
sterile equipment availability in, 132
Sydney AIDS Project Study, 68
Sydney AIDS Prospective Study, 60
symptoms, 41, 60-6
syphilis, 51
syphilis screening, 109
syringes *see* intravenous drug use; needle and syringe
Tasmania, 81, 129, 139, 148
incidence, 46-7
mortality rates, 43
tattooing, 153
Taylor Square Clinic, 69
telephone counselling, 135
television programming and advertising, 143
see also broadcasting, media
terminal care, 196
testing, 88, 98, 108-13, 157, 235, 236-43
antenatal, 113, 240-1
of breast milk donors, 54
confidentiality, 109
consent and counselling, 109-10
for employment or training recruitment, 157, 176-9 passim
the general population, 240-2, 243
groups at higher risk, 240
of hospital patients and staff, 217-18
State legislative requirements, 110
in closed institutions, 127
for life insurance purposes, 171, 172
of organ donors, organs and tissues, 111
in prisons, 139, 141
of semen for artificial insemination, 56, 111
technical aspects of, 83
see also blood screening; screening; travel
testing for the workplace, 157
ACTU policy, 152
T4+ cells, 52, 80
T4+ lymphocytes, 61
Thailand, seroprevalence in, 226
therapeutic treatment see drugs; treatment
throat and mouth soreness, 61, 64
thrush, of mouth and oesophagus, 64
toilets, 58
toothbrush sharing, 154
Touche Ross consultancy on costs and human resources, 77-82, 84, 250-1
tourism *see* travel
Toxoplasma gondii, 64
trade unions
role of for prevention in the workplace, 151-2
TRAIDS, 149-50
training
for counselling services, 193-4
for drug treatment workers, 134
for general medical practitioners, 196
for neurological aspects of treatment, 194-5
for health and support workers, 84-5
requirements for professionals, 199-200
see also occupational health and safety
training of infected people
development of policies for, 176-9
transmission, 43, 45-6, 48, 49, 126-7
policies to minimise, 89-93, 95-9, 232-3
research to minimise, 244-52
see also blood screening, education, testing
transmission modes, 45
see also epidemiology
travel and postings overseas, 115-17, 156-9, 224, 225
education for, 118-20
required testing for, 157, 225
treatment, 168-73, 187, 192-9
chemotherapeutic, 168-70
compulsory, 122-3
costs *see* economic costs
drugs, 75, 168
see also Zidovudine
needs of particular infected groups, 171-3
tuberculosis, 235-6
public health measures to combat, 112, 122
tumors, 63, 65
ulceration, 64
ulceration, genital, 51
Unemployment Benefit, 180
United Kingdom
Advisory Council on the Misuse of Drugs, 135
incidence rate reduction through needle exchange etc; and treatment programs, 54
United States of America, 39, 51
male to female ratio of incidence, 46
occupational injuries, 56-7
prevalence in children, 53, 55
prevalence in intravenous drug users, 55, 57, 118-19
prevalence ratios, 42
see also New York City
utensils, eating, 58
vaccine, 123, 232, 244, 246
vacuolar myelopathy, 64
vaginal and cervical secretions
seropositivity in, 51, 68, 121
vaginal intercourse
epidemiology, 40

Victoria, 81, 139, 188, 153
incidence, 46-7, 48, 49
mortality rates, 43
see also Melbourne
Victorian AIDS Council
Volunteer Code of Practice, 201
Victorian Prostitutes Collective
preventive programs run by, 148
virology, 246
see also National Health and Medical Research Council
virus expression, 51-2
viruses, 63
visual impairment, 64
voluntary carers, 84-5, 162-3, 196, 200-3
legal liability of, 202-3
training and support for, 74, 84-5, 89, 162, 201-3
see also community based care; program related costs; Touche Ross
Volunteer Code of Practice, 201
volunteers *see* voluntary carers
vomiting, 61
weight loss, 61, 62, 63, 64, 65
Western Australia, 81, 108, 139, 148, 153
incidence, 46-7
see also Perth
white blood cells, 61
Westmead Hospital, 169
WHO *see* World Health Organization
Widow's Pension, 181
withdrawal, 63, 65
women, 40, 41
and research into infection in, 232, 245
and voluntary testing for research purposes, 240, 241
mortality rates, 43
preventive education for, 146-7
treatment needs of, 136, 172
see also child care; perinatal transmission; prostitutes
women intravenous drug users
prevention and treatment programs for, 136-7
workers, health and support
rights and responsibilities of, 221-2
see also occupational health and safety
workers compensation, 156, 158, 222
workforce participation, 176-9, 180, 182
workplace discrimination, policies for avoiding, 151 , 152
workplace health and safety, 66
policies for prevention of transmission, 151-9
see also occupational health and safety
World Health Organization
Consultation on International Travel and HIV Infection, 115-16, 117
Global Programme on AIDS, 39, 119, 157, 224, 225, 226-7, 228
travellers information booklet, 119, 157
prevalence and projected estimates, 39
prevalence ratios, 41-2
see also Appendices 2 and 3
XTC, 98
young people
condom use, 103
preventive education for, 103, 106, 143-6
see also adolescents; children
youth training centres, preventive programs in, 145
youth workers, role of, 145-6
Zidovudine, 75, 168, 169, 170, 187
see also Touche Ross

88/20 322 Cat. No. 88 0427 0