

The National Indigenous Australians' Sexual Health Strategy 1996-97 to 1998-99

A report of the
ANCARD Working Party on
Indigenous Australians'
Sexual Health



march 1997





**The National Indigenous
Australians' Sexual
Health Strategy
1996–97 to 1998–99**

**A report of the ANCARD Working Party on
Indigenous Australians' Sexual Health**



© Commonwealth of Australia 1997

ISBN 0 642 27008 2

First printed in March 1997.

This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to inclusion of an acknowledgment of the source and no commercial use or sale. Reproduction for purposes other than these requires the written permission of the Australian Government Publishing Service, GPO Box 84, Canberra ACT 2601

Best practice examples throughout this report have been used to illustrate the successful and innovative HIV/AIDS, STDs and related communicable disease strategies being used in the primary health care sector and mainstream services. If you would like contact details for any of these best practice examples or would like an up to date listing of NACCHO and its State affiliates please contact the Department of Health and Family Services on phone (06) 289 7346 or write to the Department of Health and Family Services, Aboriginal and Torres Strait Islander Task Force, MDP 15, GPO Box 9848, Canberra ACT 2601.

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

Editor Chris Pirie



Foreword

I am very pleased to be able to present the *National Indigenous Australians' Sexual Health Strategy—the Report of the ANCARD Working Party on Indigenous Australians' Sexual Health*. HIV/AIDS and sexual health issues within Aboriginal and Torres Strait Islander communities have been of particular concern to me for a number of years and they formed a key part of the Government's election commitments on Aboriginal health. While Australia has much to be proud of in its broader response to HIV/AIDS, I am convinced that there remains a great challenge to be met in addressing these issues within Indigenous Australian communities.

This is not to say that there have not been some extraordinary successes in addressing this issue. A number of people and organisations have been actively working on ways to improve the sexual health of Aboriginal and Torres Strait Islander Australians. For example, work done in the Kimberley and in Central Australia provides a firm foundation upon which further programs can be developed.

However it is now time for a more comprehensive and coordinated response to these difficult issues.

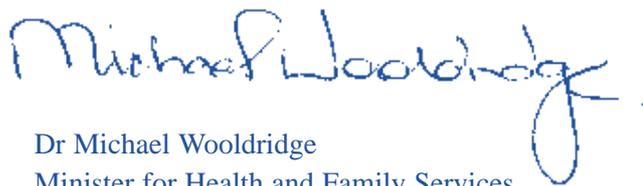
The Working Party on Indigenous Australians' Sexual Health, a working party of the Australian National Council on AIDS and Related Diseases, has conducted a comprehensive examination of the sexual health of Aboriginal and Torres Strait Islander people and clearly identifies strategies which address the specific clinical care and cultural needs of Aboriginal and Torres Strait Islander People—strategies which have not been clearly articulated previously.

The Working Party has undertaken a national consultation process with Aboriginal and Torres Strait Islander people, seeking their views on what has worked and not worked, what remains to be done and how to proceed towards a goal of substantial improvement of the sexual health of Aboriginal and Torres Strait Islander people. The Report is also underpinned by an extensive review of literature relating to the area, and the latest data regarding the sexual health status of Aboriginal and Torres Strait Islander people in this country.

One of the particular strengths of the Working Party's Report is that it is firmly based on public health evidence, some of which has only come to light in the last year. It may not be an exaggeration to suggest that some of the recent findings in regard to sexual health are the most important to come to light in

the last decade. These findings emphasise that improving the sexual health of Aboriginal and Torres Strait Islander people is not primarily a task of changing sexual behaviour. They reinforce what Aboriginal Medical Services have been telling Governments for some years, a message which the Working Party has reinforced, that improving the health of Aboriginal and Torres Strait Islander communities will depend on the provision of appropriate and comprehensive primary health care. Our challenge is to improve the level of basic primary health care in remote areas.

I thank all those people involved, particularly the members of the Indigenous Australians' Sexual Health Working Party, for their commitment to a partnership between community, service providers and governments. I believe this partnership may also be the key element to substantial improvement in the sexual health of Aboriginal and Torres Strait Islander people. The Working Party's Report will form the basis of the Government's strategy on HIV/AIDS in Indigenous communities.



Dr Michael Wooldridge
Minister for Health and Family Services





Contents

Foreword	i
Summary	1
Preface	15
Chapter 1 Where the report came from	19
1.1 The story of the Working Party	19
1.2 Developing the report	20
Chapter 2 The story so far: HIV/AIDS in Australia's Indigenous community	23
2.1 How does HIV/AIDS fit with 'sexual health'?	23
2.2 Current knowledge about HIV/AIDS, STDs and other blood-borne diseases in Indigenous Australian communities	24
2.3 The community and government response to HIV/AIDS	31
Chapter 3 Roles, responsibilities and partnerships	35
3.1 How this report fits into the 'big picture'	35
3.2 Developing this report	37
3.3 Roles and responsibilities	39
3.4 Building effective partnerships	47
3.5 Health sector reform	50
Chapter 4 Prevention	53
4.1 Introduction	53
4.2 The role of the primary health care sector	55
4.3 Improving the diagnosis and treatment of STDs	57
4.4 Collaboration and regional planning	62
4.5 Education strategies	63
4.6 Education in particular contexts	66
4.7 Harm minimisation and 'health hardware'	69
4.8 Creating a discrimination-free environment for prevention	72
4.9 The legislative framework	73

Chapter 5	Treatment, care and support	77
5.1	Introduction	77
5.2	Treatment	78
5.3	Support services	84
Chapter 6	Workforce issues	91
6.1	Resourcing	92
Chapter 7	Research and data collection	95
7.1	The Third National HIV/AIDS Strategy	95
7.2	Matters raised during the consultation process	95
7.3	Recommended strategies	96
7.4	The guidelines on ethical matters in Aboriginal and Torres Strait Islander health research	97
7.5	Research institutions	98
7.6	International models	99
7.7	Research into injecting drug use	99
7.8	Data collection	99
7.9	The National Centre for Aboriginal and Torres Strait Islander Statistics	101
7.10	The National Communicable Diseases Surveillance Strategy	101
7.11	Partnership developments	101
Chapter 8	Evaluation and monitoring	103
8.1	Reporting mechanisms	104
8.2	Developing and evaluation framework for this report	106
Appendix A		107
Appendix B		109
Appendix C		110
References		112
Glossary		114
Abbreviations		118





Summary

WHERE THIS REPORT CAME FROM

This report has been developed by a Working Party of the Australian National Council on AIDS and Related Diseases (formerly the Australian National Council on AIDS). The Council was concerned about the potential for HIV to have a particularly severe impact on Aboriginal and Torres Strait Islander communities. The establishment of the Working Party and the development of this report are a response to this concern.

The Working Party consists of Indigenous Australians with expertise in sexual health. Its purpose has been to propose a strategy for promoting and enhancing the sexual health of all Indigenous Australians.

The Working Party has been involved in an extensive program of consultation in urban, rural, remote and island areas around the country. Men's groups, women's groups and closed forums were used to ensure maximum participation and free expression. In particular, information was sought about deficiencies in, barriers to, and successes with health provision in local areas. Participants were also asked to identify priorities and local strategies for dealing with their concerns.

To complement these consultations, the Working Party also called for written submissions and undertook a review of existing literature on the subject.

THE STORY SO FAR: HIV/AIDS IN AUSTRALIA'S INDIGENOUS COMMUNITY

How does HIV/AIDS fit with 'sexual health'?

After lengthy discussions about how to define the term 'sexual health', the Working Party concluded that it was not possible to concentrate on HIV/AIDS in isolation and so adopted a definition that embraced HIV/AIDS, other sexually transmissible diseases, blood-borne viruses and sexuality. The Working Party acknowledges the obvious relationship between sexual and reproductive health, but its charter was to focus on STDs, HIV/AIDS and related blood-borne viruses such as hepatitis B and hepatitis C.

The Working Party also agreed that the term 'sexual health' encompasses a number of important personal rights, such as the right to enjoy and control sexual and reproductive behaviour, and freedom from diseases.

Current knowledge about HIV/AIDS, STDs and other blood-borne diseases in Indigenous Australian communities

It is difficult to obtain accurate information on the prevalence and incidence of HIV infection, STDs and blood-borne viruses in Aboriginal and Torres Strait Islander communities. Inconsistencies between States and Territories in the use of Indigenous identifiers and in the quality of data make any data that are collected not entirely reliable. It is, however, possible to draw some conclusions:

- Rates of HIV notification are similar in the Indigenous and non-Indigenous population. But between 1992 and 1996 the notification rate in the Aboriginal and Torres Strait Islander population increased, whereas it decreased in the non-Indigenous population.
- Sexual contact between men is the predominant mode of HIV transmission among Aboriginal and Torres Strait Islander people, but the proportion reporting heterosexual contact as the mode of transmission is higher than among non-Indigenous people with HIV.
- Compared with the non-Indigenous population, rates of notification for all bacterial STDs (such as gonorrhoea and syphilis) are substantially higher among Indigenous Australians.
- The combined rate for bacterial STDs is stable in the Indigenous population, whereas it is declining in the non-Indigenous population.
- There is a younger age distribution of STD cases in the Indigenous population and a higher proportion of female STD cases.

The community and government response to HIV/AIDS

The history of the response to HIV/AIDS in Aboriginal and Torres Strait Islander communities in Australia is characterised by the relationship between two factors:

- the development of a national, disease-specific, ‘top-down’ approach to dealing with HIV/AIDS in general;
- the development of a commitment to a holistic, primary health care approach to Aboriginal and Torres Strait Islander health.

The National Aboriginal Health Strategy, developed during the 1980s, identified sexual health as a serious concern in Aboriginal communities. At the same time, it firmly placed Aboriginal community-controlled health services at the forefront of any approach to HIV/AIDS. The Strategy marked a fundamental change in health policy, from the traditional top-down approach to one embedded in a primary health care framework. The Working Party supports this move toward a ‘horizontal’ approach for two particular reasons:



- Encouraging and supporting Indigenous participation in developing a response to sexual health concerns is crucial if the response is to be relevant and appropriate and to be implemented successfully.
- There must be a high degree of integration of different components of this report (for example, the clinical and education components) with the broader Indigenous community response to other health matters.

ROLES, RESPONSIBILITIES AND PARTNERSHIPS

How this report fits into ‘the big picture’

The recommendations from this report should form an integral part of the third National HIV/AIDS Strategy. This report gives priority to minimising HIV transmission to and between Aboriginal and Torres Strait Islander people and provides a more detailed description of how all concerned can work in partnership to achieve this aim.

Several important documents have influenced the development of Aboriginal health policy and had a particular influence on the development of this report: in particular the *National Aboriginal Health Strategy* and the Report of the Royal Commission into Aboriginal Deaths in Custody (1989).

This report also links with the National Communicable Diseases Surveillance Strategy (Department of Health and Family Services 1996a), the National Hepatitis C Action Plan, which was endorsed by the Australian Health Ministers Advisory Council in 1994, and the National Drug Strategy, which is currently being evaluated.

Roles and responsibilities

A number of bodies have an important part to play in implementing the recommendations from this report. In particular, the Australian National Council on AIDS and Related Diseases will be providing advice to the Minister on overall implementation of the National HIV/AIDS Strategy 1996–97 to 1998–99. This will include advice, provided by the Working Party, on the implementation of recommendations from this report.

Other bodies with important roles are the National Aboriginal Community Controlled Health Organisation, Aboriginal community-controlled health services, and the Australian Federation of AIDS Organisations.

The Commonwealth Government, and in particular the Department of Health and Family Services, will be very involved in both implementation and monitoring of recommendations from this report. The Aboriginal and Torres Strait Islander Health Council, the body responsible for advising the federal Minister for Health and Family Services on matters associated with Indigenous Australians' health, will play a vital part in overseeing the implementation of



the strategies from this report. Other bodies with an interest and role in implementation are the Torres Strait and Northern Peninsula Health Council and the Aboriginal and Torres Strait Islander Commission.

Building effective partnerships

The partnership approach has been fundamental to Australia's HIV policy since the beginning of organised action to combat the virus. The Working Party considers that extension of this partnership philosophy to encompass Aboriginal and Torres Strait Islander people and organisations is vital if sexual health in the Indigenous community is to be improved.

The Working Party recommends as follows:

1. that the Australian Health Minister's Advisory Council give further consideration to:
 - the need to closely monitor international events and concerns—in particular relations between the Torres Strait Islands and Papua New Guinea—that may affect the sexual health of Torres Strait Islander people,
 - development by the States and Territories of specific Indigenous sexual health strategies within the broader framework established by this report,
 - development of processes for collaboration on relevant internal cross-border matters,
 - inclusion of Indigenous Australians in State and Territory bodies that advise on HIV/AIDS and related matters;
2. that existing mechanisms for cross-border communication, cooperation and activities to improve the sexual health of the Indigenous communities of Torres Strait and Papua New Guinea be strengthened;
3. that State and Territory governments work cooperatively to redress cross-border problems within Australia, and in particular develop mechanisms for ensuring continuing treatment and care of those diagnosed with STDs or HIV;
4. that the Australian Federation of AIDS Organisations and the National Aboriginal Community Controlled Health Organisation continue to build an effective and close alliance and that similar alliance-building take place between the National Association of People Living with HIV/AIDS and NACCHO;
5. that there be regular coordination between the Australian National Council on AIDS and Related Diseases and the National Aboriginal and Torres Strait Islander Health Council.



Health sector reform

The most important policy partnership that will guide and monitor Aboriginal and Torres Strait Islander health is the Aboriginal and Torres Strait Islander health framework agreements. This partnership consists of the Commonwealth, the Aboriginal and Torres Strait Islander Commission, the State or Territory health authority, and the State- or Territory-based NACCHO affiliate. The health agreements provide for the formation of a State or Territory forum with three main responsibilities:

- to decide on how regional plans will be developed—the plans are intended to cover all health care service provision matters and to identify deficiencies and opportunities in health care provision and priorities for improving health services;
- to inform policies and decision making in relation to existing and new mainstream and Aboriginal and Torres Strait Islander-specific primary health care services;
- to evaluate the implementation of the agreement in the State or Territory.

The Working Party also notes the reform agenda agreed to by the Council of Australian Governments in June 1996, to fundamentally realign Commonwealth and State and Territory activity in health and community services. These reforms propose that Commonwealth–State funding agreements for HIV/AIDS be consolidated with other public health programs into one public health agreement for each State and Territory. The Special Funding Program, which was established under the second National HIV/AIDS Strategy to improve STD and HIV/AIDS services for Aboriginal and Torres Strait Islander communities, is being considered for consolidation.

The Working Party recommends as follows:

6. that Special Funding Program funds for HIV/AIDS not be rolled into the Public Health Agreements. Reducing the rates of STD infection and transmission of HIV among Indigenous Australians will require sustained Commonwealth leadership and an ability to press for greater collaboration.

PREVENTION

Preventing the spread of blood-borne and other sexually transmitted diseases, including HIV/AIDS, is vital to improving the sexual health of Aboriginal and Torres Strait Islander people. In this context it is important to recognise that prevention in Aboriginal and Torres Strait Islander communities will require change at a far broader level than individual behaviour. In particular, there must be better access to primary health care if sexual health is to improve. The Working Party has identified six elements that are crucial for any prevention strategy:



- the provision of high-quality, timely primary health care, particularly designed to reduce rates of STDs in Indigenous communities;
- education programs that not only provide information on reducing risks but also support broader behaviour change within communities;
- the provision of equipment that helps avoid risks—condoms, clean needles and single-use equipment for ceremonial use, for example;
- an environment free of discrimination on the basis of sexual practice, race or drug use behaviour;
- a legislative framework that facilitates, rather than inhibits, the effective implementation of the strategy;
- the development and maintenance of high-quality health information systems that provide communities with timely information on the changing profile of HIV and its related risk factors.

These elements need to be implemented through a regional framework that takes into account the diversity of need and capacity among Aboriginal and Torres Strait Islander communities.

Primary health care

The Working Party recommends as follows:

7. that existing primary health care services be strengthened by
 - ensuring treatment is based on the best, evidence-based practice, including the development and use of appropriate clinical care guidelines for diagnosis and management of STDs,
 - ensuring that clinical care guidelines are developed by those who use them and that they take account of the particular circumstances of local areas,
 - facilitating appropriate use of new non-invasive diagnostic techniques that encourage opportunistic and voluntary testing for STDs,
 - identifying and removing barriers that currently prevent the screening of non-symptomatic people,
 - using new treatment regimes that simplify the treatment of STDs—azithromycin for the treatment of donovanosis, for example,
 - developing local and regional STD screening strategies, where appropriate,
 - developing and maintaining mechanisms such as client-recall systems for follow-up of an often mobile population,



- developing and maintaining quality health information systems that provide communities with up-to-date information about changing disease profiles and related risk factors,
 - facilitating the continuing development of and commitment to confidentiality procedures,
 - developing pre-test information and post-test counselling guidelines that are culturally relevant to local communities and organisations,
 - providing training in counselling skills for Aboriginal health workers;
8. that the Commonwealth ensure that issues relating to polymerase chain reaction testing for STDs are dealt with, in order to promote and resource improvements in Indigenous sexual health care;
 9. that the Commonwealth ensure that suitable training in polymerase chain reaction testing for STDs is delivered to Indigenous health workers. Health workers should also be able to clearly explain new diagnostic techniques and their benefits and drawbacks;
 10. that the Commonwealth take the lead in disseminating to Indigenous primary health care services new information about diagnostic methods and treatments for STDs;
 11. that all Aboriginal health services be supported to develop protocols for reducing the risk of transmission of HIV and related diseases within their services, including minimising the risk of ‘needle stick’ injury, the handling of blood and body fluid spills, and infection control for medical procedures. The Commonwealth and State and Territory governments must ensure that information on best practice in these areas is collated and regularly distributed to the health services;
 12. that the question of Aboriginal health services’ safe disposal of ‘sharps’ and other potentially infectious waste, particularly in rural and remote areas, be dealt with through the State and Territory forums established under the Aboriginal and Torres Strait Islander health framework agreements;
 13. that the Commonwealth and State and Territory governments take the lead in bringing to an end testing for STDs without informed consent, particularly during routine antenatal care;
 14. that strategic partnerships between the primary health care sector and mainstream specialist organisations such as AIDS councils, public health agencies and specialist prevention and treatment services be promoted;
 15. that regional and local population health strategies for dealing with STDs be developed and implemented, in a way that enhances collaboration between primary health care services and public health agencies. This can best be achieved through the joint planning forums that have responsibility for determining how regional plans will be developed.



Education

The Working Party recommends as follows:

16. that education strategies embrace the entire community, not just people at high risk of STD and HIV transmission;
17. that education programs be designed and developed within a local community context, using local concepts and learning strategies. Continued emphasis on community-focussed education initiatives should be resourced and coordinated at a regional level and integrated with primary health care functions;
18. that the involvement of HIV-positive community members in prevention strategies be an essential part of the education approach;
19. that Aboriginal health workers be supported by relevant State and Territory education departments so they can provide effective health education for children attending schools;
20. that strategies be developed to redress the particular difficulties facing Aboriginal and Torres Strait Islander people in prison;
21. that specific attention be given to supporting existing sex worker peer education initiatives;
22. that an Indigenous emphasis be incorporated in gay community prevention programs and that messages about men who have sex with men be incorporated in Indigenous community prevention messages;
23. that the collaborative arrangements between AIDS councils and Aboriginal primary health care services be further developed;
24. that, at the national level, the Working Party ensure links between this report and the national Gay Education Strategy are developed;
25. that the Commonwealth ensure that national HIV/AIDS prevention programs and strategies are inclusive of Indigenous gay and homosexually active men;
26. that the development of local networks of trainers and educators be facilitated and include the creation of a register of trainers, speakers and support personnel that might be used to develop local or regional programs.

‘Health hardware’

The Working Party recommends as follows:

27. that the Commonwealth and State and Territory governments promote further debate about the provision of needle exchanges within Aboriginal and Torres Strait Islander communities;



28. that the success of needle exchanges in the mainstream be critically evaluated and that research be undertaken into how well these approaches translate to Indigenous communities;
29. that in those communities that already have needle exchanges there be further discussion about improving access to, and the cultural appropriateness of, those exchanges;
30. that in those communities that do not have needle exchanges there be extensive community liaison and negotiation before the introduction of such services;
31. that access to condoms be maintained and enhanced as part of education programs and primary health care;
32. that primary health care services examine strategies to increase condom use and identify barriers to their use.

A discrimination-free environment

The Working Party recommends as follows:

33. that the media commit themselves to reporting on sexual health in keeping with the media protocols developed by the Working Party;
34. that at the service level barriers to accessing mainstream specialist bodies such as AIDS councils and other agencies be identified and action taken to eliminate them;
35. that Aboriginal health services may want to consider strategies to ensure that gay men and injecting drug users feel able to access their services.

The legislative framework

The Working Party recommends as follows:

36. that possible legislative impediments to prevention and care efforts be monitored by the Working Party and that it advise the Australian National Council on AIDS and Related Diseases in this regard;
37. that the States and Territories review current HIV legislation and guidelines to ensure that legislative protection exists to protect confidentiality and is well understood by clients and services.

TREATMENT, CARE AND SUPPORT

The treatment needs of Aboriginal and Torres Strait Islander people living with HIV/AIDS, their partners, families and carers are not being met. Indigenous people are not receiving high-quality information about treatment options and they are not participating in clinical trials of new treatments. It is also evident that the care and support needs of Indigenous Australians either are not being



met or are being attended to by already over-stretched family and community networks, which in turn are not adequately supported. The Working Party notes that HIV-positive people have an important role to play in the development of treatment, care and support strategies.

Three elements are essential to successful diagnosis and management of HIV among Aboriginal and Torres Strait Islander people:

- enabling access to advances in HIV treatment programs;
- improving the capacity of primary health care services to deliver high-quality treatment and care to Aboriginal and Torres Strait Islander people;
- strengthening partnerships between Indigenous and mainstream agencies.

The Working Party recommends as follows:

38. that strategies be developed to ensure that, as knowledge about HIV disease progression increases and the range of treatment options expands, Aboriginal and Torres Strait Islander people receive up-to-date information about changes in standards of care so that they can make informed choices about treatment regimes;
39. that the Clinical Trials and Treatments Advisory Committee of ANCARD develop strategies to ensure that Aboriginal and Torres Strait Islander people have equitable access to clinical trials and the latest treatments;
40. that the Commonwealth facilitate debate with all stakeholders about the benefits of, and strategies for, early intervention for HIV/AIDS management, including encouraging the testing of people at risk and the use of existing community-level communication mechanisms;
41. that the Commonwealth take the lead in facilitating the development of guidelines for pre-test information and post-test counselling for Aboriginal and Torres Strait Islander people;
42. that the Commonwealth facilitate discussions with Aboriginal health services about the development of effective confidentiality systems and that it help primary health care services develop local strategies for assuring confidentiality;
43. that the Commonwealth and State and Territory governments ensure that the primary health care sector is adequately resourced in terms of staffing and information to enable it to provide high-quality treatment and care.
44. that mechanisms be developed for ensuring that local health care services receive up-to-date information about treatment and care. This information should be provided in formats that meet the diverse information needs of Aboriginal health workers, nurses, doctors and service managers;



45. that the Australian Federation of AIDS Organisations and the National Aboriginal Community Controlled Health Organisation work together to facilitate collaboration at the local level between Aboriginal health services and AIDS councils;
46. that the Commonwealth and State and Territory governments develop strategies to improve access to health care for people living with HIV/AIDS in rural and remote areas;
47. that, in developing and publishing action plans for HIV treatment and care in their communities, the States and Territories clearly define strategies to meet the specific needs of HIV-positive Indigenous Australians living in rural and remote communities;
48. that the Commonwealth facilitate an examination of the suitability of other funding models—such as case management, or brokerage, approaches—for the provision of support services to Indigenous Australians living with HIV/AIDS;
49. that a more coordinated approach to the provision of support for Aboriginal and Torres Strait Islander people with HIV/AIDS in rural and remote areas—which would see integration of the care of people with HIV/AIDS into the broader care and support networks of the community—be piloted and evaluated;
50. that the Commonwealth facilitate discussions with major players, including Aboriginal Hostels Ltd and the community sector, on how best to meet the housing needs of Indigenous Australians with HIV/AIDS;
51. that training in the use of the care and support resource kit being developed through the Office for Aboriginal and Torres Strait Islander Health Services be provided. National accreditation in care and support training is also a priority.

THE HEALTH WORKFORCE

Aboriginal and Torres Strait Islander health workers are integral to the work of the primary health care sector. Having a pool of trained, multi-skilled Indigenous health workers will greatly increase the capacity for developing innovative approaches to sexual health.

The Working Party recommends as follows:

52. that more positions be created for Indigenous health workers, especially for Indigenous men, given the under-representation of men and because of the gender specific nature of men's and women's business;
53. that training places available for Indigenous people wanting to become health workers be increased, especially for Indigenous men;



54. that the Commonwealth provide leadership in facilitating agreements on student intakes and career path development for Indigenous health workers;
55. that basic training for Indigenous health workers include training in sexual health and related fields such as counselling, communication and health promotion. Sexual health studies should overlap with areas such as clinical care, program development, community care, child protection, management of teams, administration and research;
56. that all sexual health training be accredited;
57. that gender-specific training be incorporated in Indigenous health worker training;
58. that links between Indigenous health workers be enhanced through professional associations, workforce initiatives, regional coordination and informal networks;
59. that other health professionals who work in Aboriginal health services be trained so that they can play an effective part in the management of sexual health. This training needs to be developed in conjunction with the relevant professional and representative bodies and in collaboration with Indigenous health bodies and training institutions;
60. that the Commonwealth facilitate further debate about the benefits associated with the development and implementation of consistent national workforce legislation.

RESEARCH AND DATA COLLECTION

Research

Two important themes emerged during the Working Party's consultations: the need for community involvement in research; and the need to use methods that take into account the range and diversity of Indigenous Australians' culture. The consultations also confirmed the need for Indigenous people's involvement in every stage of the research process.

The Working Party recommends as follows:

61. that the research agenda be focussed on managing the transmission of HIV and related diseases in the primary health care setting, and in a way that ensures community control;
62. that in Aboriginal and Torres Strait Islander communities expertise in the managing and monitoring of HIV/AIDS, STDs, hepatitis C and other blood-borne viruses be developed;
63. that priority be given to research—particularly social and behavioural research—that will shape the development of sexual health programs;



64. that in carrying out research connected with Aboriginal and Torres Strait Islander people research bodies adopt the following criteria
 - research must be developed in close collaboration with the primary health care sector,
 - research results must be disseminated at the community level,
 - research must be strategically focussed and, in particular, illuminate matters of concern to service deliverers,
 - Indigenous health workers and health service managers must have sufficient skills and knowledge to be involved in the projects and research,
 - research must be part of the community development process,
 - researchers must adhere to ethical guidelines—either those established by Indigenous people or the National Health and Medical Research Council’s Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research;
65. that the National Health and Medical Research Council’s Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health be reviewed with a view to both improving adherence to the Guidelines and expanding their coverage to include all research processes, not just research undertaken through the NHMRC.
66. that the Australian Health Ethics Committee of the National Health and Medical Research Council promote the establishment of Aboriginal and Torres Strait Islander institutional ethics committees.

Data collection

Data collection, or ‘surveillance’, remains one of the most controversial aspects of sexual health policy, although there appears to be increasing agreement on the need for relevant data. Fundamental questions remain, however, in relation to collection methods, ownership of information, confidentiality, privacy, access to data, and the ultimate use of data.

The Working Party recommends as follows:

67. that protocols be developed for collection and use of health data, including data on sexual health.

EVALUATION AND MONITORING

Evaluation and monitoring of the recommendations from this report will be vital to ensuring effective actions are taken and that these actions have met the needs of Indigenous Australians. Evaluation and monitoring will occur through a number of avenues: an annual report by the Australian National Council on



AIDS and Related Diseases to the Minister for Health and Family Services; monitoring and evaluation by State and Territory governments; and a national program of monitoring and evaluation coordinated by the Public Health Division of the Commonwealth Department of Health and Family Services.





Preface

This report is about where we want to go.

In May 1995 representatives of Aboriginal and Torres Strait Islander people met to discuss Indigenous Australians' sexual health and what was required to prevent the transmission of sexually transmissible diseases and HIV in their communities, to provide guidance on the most appropriate methods of care and support for Indigenous Australians infected with and affected by HIV, and to facilitate greater community involvement in the management and prevention of HIV.

The upshot of the meeting was the establishment of the Indigenous Australians' Sexual Health Working Party, which embarked on the mammoth task of identifying the problem and, in particular, working out where sexual health fits into the broad scheme of the Aboriginal and Torres Strait Islander health agenda.

During 1996 the Working Party held extensive consultations to elicit the views of Aboriginal and Torres Strait Islander people on a range of matters associated with sexual health. These consultations guided the development of this report. The consultation process was based on a holistic notion of sexual health: there are important links between sexual health and reproductive health, and they are acknowledged throughout this document. The Working Party considered, however, that it was not appropriate for it to provide detailed advice on reproductive health.

The development of this report has been a difficult task. Sexual health concerns private and intimate aspects of our lives. For Indigenous Australians this is a problem because in the past many health interventions have led to unwanted and unnecessary intrusion into our lives. There are also still many negative stereotypes about aspects of sexual health and sexuality.

We now have the opportunity to tackle this complex problem and to produce sustainable improvements in Indigenous Australians' health.

Many of the principles outlined in this document draw on those expressed in the National Aboriginal Health Strategy. That Strategy proposed to reduce the incidence of STDs and to limit the spread of HIV by introducing education and prevention programs through primary health care organisations. It also placed the primary health care agency at the forefront of any approach to Aboriginal and Torres Strait Islander people's sexual health. This change in emphasis, from a vertical (top-down) approach to a more horizontal, community-

controlled approach, has had an important effect on the way communities are dealing with sexual health, particularly HIV transmission. There are some good examples of community-controlled health services responding effectively to the complexities of STD control and HIV prevention.

The latest figures regarding the extent of HIV infection in Aboriginal and Torres Strait Islander communities are presented in this report. These figures show that although the total number of Indigenous Australians infected with HIV is small there are indications that the rate of infection is increasing. There is also evidence of a different pattern of transmission in the Aboriginal and Torres Strait Islander community compared with the non-Indigenous community; for example, in the Indigenous community approximately 27 per cent of the cumulative infections between 1985 and 1996 resulted from heterosexual transmission compared to 8 per cent in the non-Indigenous community. Further, there is concern about the high rates of STDs in many parts of Australia and that this may contribute to an increase in the spread of HIV. There is also growing awareness within Indigenous communities of the risk associated with injecting drug use.

The Working Party proposes a comprehensive approach to prevention, incorporating a range of strategies delivered within the primary health care context. This is important for two fundamental reasons. First, the links between activities such as health education, clinical care and other health initiatives need to be improved. Second, and more important, Indigenous communities need a mechanism for engaging with these problems in a way that takes into account cultural diversity and the range of local concerns that must be considered alongside matters related specifically to sexual health. Community control of, or community participation in, developing prevention activities is a natural extension of the principle of partnership that has been the basis of Australia's broader response to HIV/AIDS.

The treatment and care of people with HIV/AIDS has been acknowledged as an important issue for Indigenous Australians. There is much to be done to improve the current fragmented approach. New treatment programs offer the potential for improved life quality and expectancy for people living with HIV, but Indigenous people are yet to benefit from them. Consistent with the third National HIV/AIDS Strategy, this report recommends integration of the treatment and care of people living with HIV within the primary health care context. If this is to be successful, primary health care services must be effectively supported in providing high-quality treatment and care. Important to this will be the development of local-level partnerships between Aboriginal community-controlled health services and the mainstream treatment and care agencies. These partnerships should help to provide greater choice to infected and affected people as well as promote continuity of care between primary carers and specialist agencies.



Effective approaches to Indigenous sexual health require a properly resourced workforce in the Aboriginal primary health care sector. This matter will require some attention in the implementation of this report. In particular, it is important that Aboriginal health workers have opportunities to develop their skills in the area of sexual health.

To date, Indigenous Australians have had limited, if any, control over research and the collection of health data. A number of controversies have resulted from breaches of confidentiality and privacy and from inadequate consultation in the development of research and data-collection processes. But research and data collection are very important if we are to respond effectively to the challenges posed by STDs, HIV/AIDS, hepatitis C and other related communicable diseases. The Working Party makes a number of recommendations designed to improve collaboration between communities and research institutions. It also recommends that there be greater attention to the ethical problems associated with data collection, as well as problems associated with the quality of health information systems.

Evaluation will be vital to the success of implementing this report's recommendations. The Working Party has been keen to ensure that clear benchmarks are established, so that progress can be monitored. It is also aware that numbers are not the only form of measurement and that success will depend on the strength of the partnerships between all levels of government, the National Aboriginal Community Controlled Health Organisation and its affiliates, and those mainstream organisations that have expertise in sexual health.

The third *National HIV/AIDS Strategy* strongly endorsed a framework for collaboration and coordination between all those involved and this should be reflected in the implementation of the recommendations arising from this report.

We take this opportunity to thank all those who worked to develop this report; they put in an immense amount of time and effort to ensure that the consultations were successful and that Aboriginal and Torres Strait Islander people were able to have a say in the construction of what is the first national sexual health report created by and for Indigenous Australians.



Dr Ian Anderson



Ms Debra Reid





Where the report came from

1.1 THE STORY OF THE WORKING PARTY

The Australian National Council on AIDS (now the Australian National Council on AIDS and Related Diseases) is the Commonwealth Government's principal advisory body on HIV and AIDS. It was established in 1995 under the second National HIV/AIDS Strategy to provide the Commonwealth Minister for Health with independent and expert advice on the implementation of the first and second Strategies and to identify national HIV/AIDS priorities and needs.

A growing concern about the sexual health of Aboriginal and Torres Strait Islander people prompted ANCA to convene, between 14 and 17 May 1995 in Alice Springs, an Aboriginal and Torres Strait Islander Forum on Sexual Health. The establishment of an ANCA Working Party on Indigenous Australians' Sexual Health was one result of the Forum. Nominations for the Working Party were sought from the Forum and from the Aboriginal and Torres Strait Islander Commission, the National Aboriginal Community Controlled Health Organisation, the Torres Strait Islander Advisory Board and the Torres Strait and Northern Peninsula Health Council. The Working Party's challenge was to develop a strategic plan to promote and maintain the sexual health of all Indigenous Australians.

ANCA endorsed a proposal that a panel be established to select members of the Working Party following receipt of nominations: the panel was made up of individuals working in the area of Indigenous Australians' health; members of the Working Party were selected on the basis of expertise in clinical management, education and training, policy development, community development, and program management. To ensure Indigenous people's control of this report, the Working Party was formed using six further criteria:

- There must be a majority representation of Indigenous Australians.
- Fifty per cent of the members must be individuals representing Aboriginal and Torres Strait Islander community-controlled health services.
- A position on the Working Party must be reserved, either initially or at a later date, for an Indigenous Australian living with HIV/AIDS.
- As far as possible there should be a balance of members across States and Territories.

- Members should have expertise in the area of sexual health.
- There should be the capacity to co-opt, as necessary, individuals with specific skills to help the Working Party.

Dr Ian Anderson chaired the Working Party until November 1996, when Ms Debra Reid took over the role of chairperson. Other members of the Working Party were Ms Stephanie Bell, Mr Sol Bellear, Mr Colin Ross, Mr Neville Fazulla, Mr Michael McLeod (member until December 1996), Ms Pat Swan (member since January 1997), Ms Vicki Jones, Ms Edna Brown, Ms Yoko Nakata, Ms Elsie Nawia, Ms Debra Bennell, Mr Rob Guest (member until July 1996), and Mr Trevor Woodhead (who was an independent member of the ANCARD Education and Prevention Sub-committee, and was also co-opted to help the Working Party; has been a member since January 1997).

Two additional members—ANCA’s Ms Vanessa Read (until May 1996) and Mr Bill O’Loughlin—were involved in the Alice Springs Forum. Representatives from the Public Health Division and the Office for Aboriginal and Torres Strait Islander Health Services, both within the Department of Health and Family Services and the Aboriginal and Torres Strait Islander Commission attended as observers.

The purpose in establishing the Working Party was to develop a strategic plan to promote and maintain the sexual health of all Indigenous Australians. The terms of reference for the Working Party during development of the report were as follows:

- to develop a national strategic plan aimed at promoting and maintaining the sexual health of all Indigenous Australians, in reducing the level of STDs and in preventing the spread of HIV infection in their communities;
- to monitor and provide advice to ANCA on the implementation of the recommendations from the ANCA Aboriginal and Torres Strait Islander Forum on Sexual Health held in Alice Springs on 14–17 May 1995;
- to advise on Aboriginal and Torres Strait Islander sexual health issues, particularly surveillance, diagnosis, management, care and support, preventive education, control measures, research and evaluation for all STDs including HIV/AIDS in Aboriginal and Torres Strait Islander communities;
- to advise on appropriate staffing and resourcing of Indigenous Australian communities in the HIV/STD services in order to accommodate responses and recommendations through best-practice principles.

1.2 DEVELOPING THE REPORT

The Working Party has been committed to the principles of self-management, self-determination, and the promotion of Indigenous people’s re-empowerment.



In recognition of these principles and to ensure that Aboriginal and Torres Strait Islander people were able to contribute directly to sexual health policy and program development at a national level, the Working Party embarked on an extensive program of consultations, called for written submissions, and conducted a thorough literature review and analysis.

1.2.1 Consultation

Fifty-four regional consultations within Indigenous communities were held in urban, rural, remote and island areas around the country (see Appendix A).

Working Party members were very conscious of the question of accountability—first and foremost to Indigenous Australians—and this was reflected in their consultation process. The consultations were managed within a framework respectful of the diversity of cultural values, processes and protocols. Men’s groups, women’s groups and closed forums were used to ensure maximum participation and to encourage free expression. Participants were asked to provide feedback on the appropriateness of the consultation process for identifying concerns about sexual health, and this feedback was continually used to monitor and review the consultation process.

The Working Party was particularly interested in ensuring that Indigenous Australians’ depth of knowledge about sexual health informed the development of the report. Participants were encouraged to discuss deficiencies in and barriers to health service provision and to celebrate successes in their local areas. They were also asked to identify priorities and local strategies for dealing with them.

The consultations and the feedback contributed greatly to the development of this report and provided valuable information about emerging trends across the country as well as individual needs and priorities for specific groups and regions.

1.2.2 Written submissions

To ensure that those who were unable to participate in the regional consultations had a chance to have their voices heard, invitations for written submissions were advertised in the Indigenous and non-Indigenous print media as well as on Indigenous radio networks. Additionally, key stakeholders, including Aboriginal community-controlled health organisations and their peak representatives, were invited to prepare written submissions and to contribute to the process of identifying gaps and barriers at a national level.

Twenty-six written submissions addressing the Working Party’s terms of reference were received from State health departments, peak organisations, community-controlled health services, medical practitioners, and other individuals (see Appendix B).



1.2.3 Literature review and analysis

A further mechanism used by the Working Party was to undertake a substantial review and analysis of existing literature as well as related national and State and Territory reports and strategies. The Working Party paid particular attention to three reports:

- the report of the Aboriginal and Torres Strait Islander Forum on Sexual Health, held in Alice Springs from 14 to 17 May 1995 (ANCA 1995);
- the report of ‘Anwernekenhe’: the First National Aboriginal and Torres Strait Islander Gay Men and Transgender Sexual Health Conference, held at Hamilton Downs in the Northern Territory from 31 October to 4 November 1994 (Anwernekenhe Conference Committee 1994);
- the Review of Research and Program Findings Relating to the Sexual Health of Aboriginal and Torres Strait Islander people (Reid 1996).





The story so far: HIV/AIDS in Australia's Indigenous community

2.1 HOW DOES HIV/AIDS FIT WITH 'SEXUAL HEALTH'?

Initially, the Working Party interpreted 'sexual health' as specifically relating to HIV and AIDS, but it quickly became apparent that the problem of HIV/AIDS cannot successfully be addressed in isolation from other sexually transmitted diseases, related blood-borne viruses and sexuality.

For Indigenous Australians, sexual health is closely linked to well-being. And for most Indigenous Australians, well-being is not a narrow experience of the physical body: it is also a cultural, emotional and spiritual experience.

Australia's Indigenous men and women have distinct cultural traditions, which have historically defined the manner and place in which sex and sexuality may be discussed. The poor sexual health status of Indigenous Australians in contemporary Australia has, however, seen matters integral to our understanding of HIV/AIDS and STDs being more publicly discussed by Aboriginal and Torres Strait Islander people and their communities.

There is not universal support for the use of the term 'sexual health' in this context. Some communities prefer to use 'women's business' and 'men's business', while others refer simply to STDs and HIV/AIDS programs. The Working Party considers that local communities should use whatever terminology they are most comfortable with. After much debate the Working Party has taken 'sexual health' to include the following personal rights:

- the right to enjoy and control sexual and reproductive behaviour in accordance with cultural values, kinship practices and individual ethics;
- freedom from fear, shame, guilt and myths about choice of sexuality and sexual relationships;
- freedom from diseases that are treatable or preventable, or both, and that may interfere with sexual life;
- freedom from practices that may interfere with the sexual health and emotional well-being of the individual.

Sexual health is the right of all people, regardless of their income, age, ethnic background, language, gender, religion, sexual orientation, literacy level, disability or geographical location. It contributes to the enjoyment of life.

Four aspects of our lives that help us achieve sexual health are the ability to make informed choices about healthy behaviour and lifestyles, the ability to enjoy and express sexuality without guilt or shame in fulfilling relationships, control of our own fertility, and avoiding behaviours that damage our overall health.¹

The Working Party recognises the importance of reproductive health for Indigenous Australians and acknowledges that there is an important relationship between sexual health and reproductive health, especially in relation to the following:

- aspects of antenatal care, especially screening for and treatment of STDs and HIV in pregnant women and babies;
- the effect STDs have on the ability of Aboriginal and Torres Strait Islander women to have children;
- the need for men to understand their role in protecting their unborn babies.

Although there is an obvious synergy between reproductive health and sexual health, the Working Party concluded that its charter was to focus primarily on matters specifically relating to sexual health, including STDs, HIV and other blood-borne viruses. Strengthening primary health care services will also benefit other aspects of Indigenous health.

2.2 CURRENT KNOWLEDGE ABOUT HIV/AIDS, STDs AND OTHER BLOOD-BORNE DISEASES IN INDIGENOUS AUSTRALIAN COMMUNITIES

It is difficult to obtain accurate information on the prevalence and incidence of HIV infection, STDs and blood-borne diseases in Aboriginal and Torres Strait Islander communities. Inconsistencies between States and Territories in the use of Indigenous identifiers and in the quality of data collected limit its usefulness. The Epidemiology Unit of the National Centre in HIV Epidemiology and Clinical Research has, however, closely examined the available data on Aboriginal and Torres Strait Islander sexual health for the Working Party, and this section of the report is based on the Unit's work. Using its own data, data obtained through the National Notifiable Diseases Surveillance System, published papers and other reports, the Unit has drawn a number of conclusions about STDs and blood-borne viruses among Indigenous Australians. In particular, it notes the following:

- Statistics on STD rates among Indigenous Australians are not available for Victoria, Tasmania and the Australian Capital Territory, and there is

¹ This is acknowledged as a World Health Organisation definition that has been modified by the Working Party.



only limited recording of Indigenous status in STD notifications from Queensland and New South Wales.

- Non-Indigenous population rates for STDs are based on the combined notifications of people classed as non-Indigenous and people whose cultural background is unknown. This reduces the validity of any comparison between Indigenous and non-Indigenous rates.
- Compared with the non-Indigenous population, the rates of notification for all bacterial STDs among Aboriginal and Torres Strait Islander people are substantially higher.
- In the Indigenous Australian population the combined rate for bacterial STDs is stable —gonorrhoea is increasing, chlamydia is stable, and syphilis is decreasing. In the non-Indigenous population the combined rate is declining.
- In the Indigenous population there is a younger age distribution of STD cases compared with the non-Indigenous population, and there is a higher proportion of female STD cases among Indigenous Australians.
- Comparing Indigenous and non-Indigenous populations, the rates for bacterial STDs are higher among Indigenous Australians than for viral STDs such as herpes and blood-borne viruses.
- There is a similar rate of HIV notification in the Indigenous and non-Indigenous populations. But for the period 1992 to 1996 the rate is increasing among Aboriginal and Torres Strait Islander populations and decreasing in the non-Indigenous population.
- There are limited data to assess rates of hepatitis C infection in both the Indigenous and non-Indigenous populations.
- There is the potential for bias in the reported STD rates for men and women because women are more likely to be screened antenatally for STDs.
- The decline in syphilis notifications may be the result of changes in testing practices and data-collection mechanisms rather than indicating a true decline in incidence.

The Working Party is concerned by incidents of irresponsible and sensationalist reporting of matters connected with HIV, STDs and blood-borne viruses. (This is discussed in Chapter 4.) Accurate reporting of the current impact of these diseases is important for informed debate, but the Working Party stresses that this information should be considered in the broader context of Indigenous Australians' health status. The Working Party also stresses that any reporting of these matters must comply with the media protocols it has developed (see Appendix C).



2.2.1 Limits to the national notifiable diseases data collection

Each Australian State and Territory is responsible for monitoring and control of communicable diseases, including STDs. National surveillance data are severely limited by the differences in surveillance systems: there are differences in both which STDs are notifiable and the bodies that are responsible for notification. Any comparison of notification data must therefore be done cautiously. In addition, some of the perceived trends in notifications of STDs may be the result of changes in definition.

The reported lower rates of STDs among the Indigenous population in Queensland are to some extent a reflection of non-reporting of Indigenous status. In contrast, Indigenous population STD rates in States such as South Australia, where reporting of Indigenous status is near complete, are much more reliable.

2.2.2 HIV infection

The deficiencies in our knowledge about HIV infection within the Aboriginal and Torres Strait Islander population have often led to 'best guesses' about the state of HIV. This has occasionally resulted in HIV/AIDS in Aboriginal and Torres Strait Islander communities being represented as a 'black developing country problem', as opposed to a 'white Australian problem'. Such simplistic notions can lead people to make false assumptions about the nature of the threat of HIV/AIDS in Australia's Indigenous communities and so hamper the development of appropriate strategies for tackling the threat.

Table 2.1 shows notifications of HIV and AIDS and deaths from AIDS among Aboriginal and Torres Strait Islander people, by sex and State and Territory, to 31 December 1996. There have been 128 notifications of HIV infection, 50 reported cases of AIDS, and 34 AIDS deaths. As with non-Indigenous people, the majority of cases have been in males. Information on exposure category demonstrates that, again as with non-Indigenous people, sexual contact between men is the predominant mode of HIV transmission (see Table 2.2). The proportion of Indigenous people reporting heterosexual contact as the mode of HIV transmission is much higher than among non-Indigenous people—27 per cent compared with 8 per cent. As with the overall pattern of HIV infection, there appears to be a trend towards an increasing proportion of heterosexually acquired cases in the Indigenous community, although numbers remain low.

In New South Wales, Queensland and Western Australia there is little difference between Indigenous and non-Indigenous people in the rate of HIV notification; in South Australia the rate among Indigenous people is higher; in the Northern Territory Indigenous people have substantially lower rates of notification. The rate of HIV notification among the Indigenous population has increased between 1992 and 1996, in contrast to the declining rate among the non-Indigenous population.



Table 2.1 Notifications of HIV, AIDS cases and AIDS deaths among Indigenous adults, by sex and State or Territory, cumulative to 31 December 1996

State/Territory	HIV notifications			AIDS diagnoses			Death following AIDS		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
NSW	29	1	30	12	1	13	5	1	6
NT	7	0	7	3	0	3	2	0	2
Qld	45	7	52	23	2	25	17	2	19
SA	11	1	12	2	1	3	2	1	3
WA	14	13	27	4	2	6	3	1	4
Total	106	22	128	44	6	50	29	5	34

Note: Since 31 December 1996 information on HIV or AIDS diagnosis by Indigenous status has not been available. New South Wales has collected a significant level of data on Indigenous status only since 1992.

Table 2.2 Exposure category for HIV notifications among Indigenous Australians, 1985 to 1996

Year	Number of cases					Total
	Hom./bis.	Hom./bis IDU	IDU	Heterosexual	Other/Unknown	
1985 to 1987	13	3	1	0	0	17
1988	3	0	0	2	0	5
1989	7	1	1	2	1	12
1990	3	2	1	1	0	7
1991	3	1	0	2	0	6
1992	7	1	0	2	1	11
1993	10	0	1	4	0	15
1994	7	3	0	8	1	19
1995	7	3	0	9	1	20
1996	9	0	2	4	1	16
Indigenous total	69 (54%)	14 (11%)	6 (5%)	34 (27%)	5 (4%)	128
Australian total	(80%)	(3%)	(5%)	(8%)	(4%)	

Note: The data are from Queensland, South Australia and Western Australia only

Neilsen and Hill (1993) reported 29 cases of HIV infection among Indigenous Queenslanders between 1984 and 1991. Ninety per cent of these cases were male and the major HIV exposure category was homosexual or bisexual contact (69 per cent). Based on these cases, the prevalence of HIV infection among the Indigenous and non-Indigenous populations in Queensland was comparable, although a higher proportion of symptomatic disease among Indigenous people suggested a larger proportion of undiagnosed HIV infection.



Although HIV prevalence among Aboriginal and Torres Strait Islander people appears to be low, the recent increase in the rate of diagnoses, including trends to a higher proportion of heterosexually acquired cases of HIV, gives cause for concern that, without significant intervention, HIV infection rates will continue to rise. This concern is strengthened by a number of factors, including the reported high rates of STDs such as donovanosis, gonorrhoea, syphilis and chlamydia in some regions, the mobility of Indigenous people, the over-representation of Indigenous people in prisons, and alcohol and substance use problems, which may mitigate against safe sex practices.

2.2.3 Sexually transmissible diseases

Many Aboriginal and Torres Strait Islander communities have extremely high rates of STDs; these contribute to a disproportionate level of morbidity and constitute an important health problem in their own right. STDs are also believed to increase the likelihood of HIV transmission, particularly if they cause genital ulceration. Although STD rates among non-Indigenous homosexual men and female sex workers have declined substantially, a similar decline has not been observed nationally among Indigenous Australians.

Gonorrhoea

National Notifiable Diseases Surveillance System gonorrhoea notifications for 1992 to 1995 demonstrate an increasing rate of gonorrhoea among the Indigenous population and stable rates among the non-Indigenous population. Reported rates among Aboriginal and Torres Strait Islander populations in Western Australia, the Northern Territory and South Australia are considerably higher than in New South Wales and Queensland, and are 10 to 150 times higher than among the respective non-Indigenous populations. The lower rate among Queensland Indigenous people compared with elsewhere partly reflects the low proportion (under 10 per cent) of notifications with Indigenous status recorded.

For notifications in the Indigenous population the male:female ratio was 1.6:1, compared with 5.5:1 in the non-Indigenous population. The peak incidence of gonorrhoea occurred in men and women between the ages of 20 and 24 years, for both the Indigenous and non-Indigenous populations. For Indigenous people, however, a higher proportion of cases occurred in younger age groups.

Syphilis

As with gonorrhoea, a large disparity exists between notification rates for syphilis among Indigenous and non-Indigenous Australians. In contrast with gonorrhoea, however, National Notifiable Diseases Surveillance System data show declining syphilis notifications in both the Indigenous and non-Indigenous populations. There has been a substantial reduction in syphilis notifications among the indigenous populations of Western Australia, the



Northern Territory, Queensland and South Australia between 1992 and 1995. Again, the lower rate of notification among Queensland Indigenous people compared with elsewhere partly reflects the lower proportion (under 10 per cent) of notifications with Indigenous status recorded.

The male:female ratio for Indigenous people was 1:1, compared with 2:1 for the non-Indigenous population. For Indigenous women the prevalence of syphilis was highest between the ages of 15 and 19 years, whereas for men prevalence was highest between the ages of 20 and 24 years. These data may reflect more extensive screening in women during pregnancy. Overall, Indigenous people with syphilis were younger than non-Indigenous people with syphilis, with the peak of notifications in the 15 to 19-year age group, in contrast with the non-Indigenous population, where most were in the 25 to 29-year age group.

Chlamydia

Chlamydia became a notifiable infection in all States and Territories except New South Wales between 1987 and 1993; in New South Wales, sexual health centres notify numbers of patients diagnosed with chlamydia by sex. The rate of chlamydia notifications in the Northern Territory, Queensland and South Australia has declined among both the Indigenous and non-Indigenous populations between 1992 and 1995. In contrast, Western Australia has had a stable rate of notifications among the non-Indigenous population but an increasing rate among the Indigenous population; this increase may be related to the increasing proportion of notifications that record Indigenous status rather than representing a true increase in incidence.

In the Northern Territory, South Australia and Western Australia rates of chlamydia are three to 16 times higher among Indigenous populations compared with non-Indigenous populations. The lower notification rate among the Indigenous population of Queensland is almost certainly indicative of the low proportion of notifications (under 10 per cent) with Indigenous status recorded, rather than representing a true decrease in incidence. Higher rates may also reflect the extent of STD screening.

Donovanosis

In Australia, donovanosis occurs almost exclusively among Indigenous populations and recurs relatively frequently among some central and northern Australian Indigenous communities. Donovanosis causes severe ulcerative disease and is of particular concern as a potential co-factor in HIV transmission.

It is generally recognised that there is considerable under-reporting of donovanosis (Hart 1995). A study involving active surveillance in the Northern Territory discovered 115 cases of treated donovanosis compared with 35 cases notified through the normal surveillance mechanisms.



Donovanosis is notified to the National Notifiable Diseases Surveillance System by the Northern Territory, Queensland and Western Australia. Notification data suggest a relatively stable incidence between 1992 and 1995, with the highest rates recorded from the Northern Territory. As noted, however the considerable under-reporting of cases makes any assessment of incidence trends difficult.

It is important to note that improved monitoring of STD rates, contact tracing and diagnosis methods in some States and Territories have resulted in a lowering of STD rates in some communities. This is why the Working Party emphasises the need for access to high-quality primary health care.

2.2.4 Other blood-borne diseases

The extent of injecting drug use among Australia's Indigenous people is unknown, but anecdotal evidence suggests that it occurs in both urban and rural communities. Information on exposure categories for HIV infection shows that 5 per cent of total infections among Indigenous people (six out of 128 cases) were due to injecting drug use. There was an additional 11 per cent of cases (14 out of 128 cases) for which the exposure category was homosexual or bisexual contact or injecting drug use, or both.

The very high imprisonment rates for Indigenous people in Australia make continued exposure to unsafe injecting behaviour and the increased incidence of intravenous drug use a serious problem, inside and outside prison. Recent findings, including those of studies in Melbourne, Brisbane, Adelaide and the Kimberley, support the need for urgent action in this area and provide insights into innovative strategies for dealing with this problem in different communities.

Hepatitis C

Notifications in the Northern Territory and Western Australia suggest that hepatitis C is less prevalent among Indigenous than non-Indigenous people. The notifications are, however, dependent on the extent of testing and the particular populations tested.

A national survey of hepatitis C prevalence among injecting drug users attending needle exchanges was conducted in the past two years (NCHECR 1997). The survey found hepatitis C prevalence among Indigenous injecting drug users to be 72 per cent (34 out of 47) in 1995 and 70 per cent (46 out of 66) in 1996. This did not differ significantly from the prevalence among non-Indigenous injecting drug users.

At present, the main way of transmitting hepatitis C is by the sharing of contaminated equipment by injecting drug users. Increased injecting behaviour among Indigenous Australians will increase the risk of the disease. Hepatitis C is difficult to manage: often people who are infected with the virus have no symptoms or symptoms that are non-specific (such as stomach pain and a loss of appetite), so diagnosis is problematic; additionally, there is no vaccine



available for the disease and only a small number of people have been reported to benefit from available treatment.

Knowledge of the incidence and prevalence of hepatitis C and associated risk factors in the Indigenous Australian population is limited. There is a need for further research to determine incidence and prevalence and prepare for the future.

A study of hepatitis B and hepatitis C prevalence in Victorian prisons concluded that both diseases were spreading rapidly through some populations of injecting drug users (Crofts et al 1995). Whilst Indigenous inmates constituted only 4.3 per cent of the sample, the study results do give cause for concern about the impact of custodial environments on the spread of blood-borne viruses. Those most at risk were young men aged less than 30 years and engaging in injecting drug use and other high-risk behaviour at the time of imprisonment. Rates of spread in this group were found to be extreme and the group constituted a sizeable at-risk population for the spread of HIV. One of the main findings concerned the lack of integrated harm-reduction programs within prison or on transition from prison.

Hepatitis B

Using National Notifiable Diseases Surveillance System data to determine rates of hepatitis B infection among the Indigenous population is difficult because of the low rates of notification of Indigenous status. Nevertheless, reports from States and Territories with significant (more than 10 per cent) reporting of Indigenous status suggest that hepatitis B is much more common among Indigenous people. Incident cases, which are a measure of recent transmission, are four to 26 times higher among Indigenous people; the greatest disparity occurs in Western Australia.

As a blood-borne disease, hepatitis B poses many of the risks posed by hepatitis C. The main transmission concerns are 'needle stick' injuries and exposure to blood or body fluids (health care workers, sexual partners, sharing of needles, and mother to neonate).

Hepatitis B vaccination should be available to all who work in the primary health care setting, particularly Aboriginal health workers—a recommendation to this effect was endorsed at the 121st session of the National Health and Medical Research Council in June 1996.

2.3 THE COMMUNITY AND GOVERNMENT RESPONSE TO HIV/AIDS

Early in the progress of the HIV/AIDS epidemic in Australia community groups and governments were aware of the potential for Australia's Indigenous people to be at particular risk of infection. There is a strong history of Indigenous men and women expressing concern about HIV/AIDS and its impact on their communities and families. These people have played a vital role in setting and maintaining the overall direction of policy and action to deal with HIV.



Following the development and publication of a policy discussion paper, *AIDS: a time to care, a time to act* (Department of Community Services and Health 1988), a process of extensive consultation began. The belief that Indigenous people were at particular risk of HIV/AIDS led to the establishment of the Working Panel on Aboriginal and Torres Strait Islanders and HIV/AIDS.

The consultation process revealed extensive support for the development of a national HIV/AIDS strategy in Australia. The *National HIV/AIDS Strategy—a policy information paper*, commonly referred to as the first National HIV/AIDS Strategy, was published by the Department of Community Services and Health in August 1989. The Strategy was informed by the consultation process and the work of six expert panels, one of which was the Working Panel on Aboriginal and Torres Strait Islanders and HIV/AIDS.

Many, notably the media, sensationalised HIV/AIDS around this time, whipping up concern about the possibility of the virus wiping out large sections of Indigenous communities. This concern was also being expressed more broadly: among other things, the quarantining of people with HIV was being debated. There was growing pressure for more urgent, centrally coordinated action on HIV/AIDS in Aboriginal and Torres Strait Islander communities. A mix of factors led to this pressure:

- Indigenous Australians confronted far greater social, health, economic and structural disadvantages than mainstream Australians.
- Matters associated with HIV/AIDS and sexual health could be lost among the many competing health priorities at the local level, in particular the need for basic environmental health infrastructure, such as water.
- There were acknowledged high rates of STDs (noted as a key risk factor in the spread of HIV) among Indigenous Australians.
- That there was a relative lack of established public health mechanisms in Indigenous communities.
- There was an almost total lack of appropriate data and research in the field.
- There were continuing discriminatory attitudes towards Indigenous men who were gay and there was a widespread belief that HIV was a disease that affected only gay white men.
- There was some denial of the existence of high-risk behaviours, such as injecting drug use, in some communities.
- Effective mechanisms for the development and delivery of health services to Indigenous communities were lacking.
- The incarceration rates for Indigenous men were extremely high.



Despite the emphasis on approaching HIV in a vertical, or top-down, way at this time, there was increasing awareness that such an approach would have limited success in Aboriginal and Torres Strait Islander communities. In particular, it was recognised that Indigenous communities were diverse and that successful approaches in one community were not necessarily transferable to another. There was also a change in the general approach to program development in Indigenous communities. The establishment of the Aboriginal and Torres Strait Islander Commission in 1991 led to a new focus on the need for self-determination, at both the community level and as an integral part of broader policy development and program delivery at Commonwealth and State and Territory levels.

The National HIV/AIDS Strategy 1993–94 to 1995–96, developed in response to the evaluation of the first National HIV/AIDS Strategy, did not depart fundamentally from the 1989 approach but focussed on strengthening and consolidating the Australian response to HIV/AIDS. Throughout the first and second National HIV/AIDS Strategies many significant Aboriginal and Torres Strait Islander programs were implemented, at local and broader levels: community meetings were held, support groups were formed, awareness was raised, educational programs were developed, and political action was taken. Community activities were essential in developing an Indigenous perspective on important aspects of sexual health. Action during this last decade at community and government levels has had a number of consequences, among them the following:

- the development of pools of expertise in sexual health among Aboriginal health workers;
- more open discussion by Indigenous Australians of questions integral to our understanding of HIV/AIDS;
- a number of developments at a policy level, such as an understanding that the response to Indigenous sexual health needs to be coordinated at multiple levels;
- an acceptance that education and prevention and treatment and care should meet the requirements of individuals, their families and communities;
- recognition of the need to acknowledge the diversity of social and cultural contexts in Indigenous communities;
- the establishment of research guidelines and treatment protocols in some areas;
- the placement of sexual health within a more holistic primary health care context.



The National Aboriginal Health Strategy, developed during the 1980s, identified sexual health as a significant health problem in Aboriginal communities. The Strategy stressed the importance of primary health care approaches to dealing with high rates of STDs and with the possibility of HIV infections.² It firmly placed Aboriginal community-controlled health services at the forefront of any approach to dealing with HIV/AIDS.

This development in health policy sees a move from a traditional top-down approach to an approach embedded in a primary health care framework. The National Indigenous Australians' Sexual Health Working Party supports this fundamental change for two main reasons:

- Active support of Indigenous participation in developing a response to sexual health matters is crucial to the relevance, appropriateness and implementation of the response.
- There must be a high degree of integration of different components of this report (for example, the clinical and education components) with the broader Indigenous community response to other health problems.

Although there has been a shift from a vertical to a horizontal approach, three particular elements of a vertical approach still need to be maintained:

- national coordination and leadership
- an evidence-based framework
- good information bases and information systems.

² The National Aboriginal Health Strategy working definition of primary health care is 'Essential health care based on practical, scientifically sound, socially and culturally acceptable methods and technology made universally accessible to individuals and families in the communities in which they live through their full participation at every stage of development in the spirit of self-reliance and self-determination' (National Aboriginal Health Strategy Working Party 1989).





Roles, responsibilities and partnerships

This chapter deals with the links with other national policies and strategic approaches; the roles and responsibilities of those with an interest in this report; and a framework for the development of strategic partnerships. Responsibility for initiating these partnerships lies with all elements of the partnership. It should be noted that any changes in the broader health reform agenda may affect the roles, responsibilities and partnerships.

3.1 HOW THIS REPORT FITS INTO ‘THE BIG PICTURE’

3.1.2 The National HIV/AIDS Strategies 1989–90 to 1992–93 and 1993–94 to 1995–96

Australia was one of the first countries to formalise its response to the HIV/AIDS problem in a national strategy. Australia’s first Strategy was published in 1989; it constituted the formalisation of programs and funding commitments dating back as far as 1983. In the epidemiological context of the time, the imperatives of the first Strategy were to contain the incidence and prevalence of HIV infection within the population of homosexually active men in which it first appeared, to reduce the rate of infection within that group, and to ensure that the virus did not become endemic in injecting drug user communities and from there spread through the wider community, as has happened overseas.

Australia’s Indigenous people were recognised as a priority for the first Strategy, which emphasised HIV education in a primary health care context and integrating it with drug and alcohol programs. A large proportion of funding was set aside for education and prevention initiatives. In response to the evaluation of the first Strategy, the National HIV/AIDS Strategy 1993–94 to 1995–96 placed increasing emphasis on HIV in a broader sexual health context and on the need for Indigenous Australians to be actively involved in strategic planning at the State and Territory level.

Both the Strategies foresaw two important challenges in the second decade of HIV in Australia: to halt the spread of the virus through behaviour change; and to provide support to those already infected with HIV and to increase their chances of long-term survival. It was noted in the second Strategy that HIV infections appeared to have stabilised and that most new infections were continuing to occur among homosexually active men.

A partnership approach was one of the foundations of both Strategies. But, although they stressed the need to be aware of and respond to the problems of HIV/AIDS in Indigenous communities, to date Indigenous organisations have had little formal involvement as active members of the partnership arrangement and related organisational structures.

The Feachem report—a major evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96 (Department of Human Services and Health 1995)—found that high rates of HIV infection among injecting drug users, sex workers and heterosexuals had so far been avoided, but that rates of HIV infection among homosexually active men remained unacceptably high. It noted with concern trends in HIV infection in Aboriginal and Torres Strait Islander communities and recommended urgent action in developing an effective HIV prevention strategy. The report concluded that the national policy response to these problems should have five elements:

- Work must proceed in close partnership with Aboriginal and Torres Strait Islander communities and in full recognition of their multiple health and social disadvantages.
- Program funding should be increased to correspond with the size of the problems that must be confronted.
- Better social, behavioural and epidemiological data are required in order to accurately define and describe the problems involved.
- Better evaluation of projects and programs is required so that knowledge of what approaches work best can be developed over time;
- Community-based care and medical preparedness to deal with HIV must be improved by encouraging greater acceptance, across all health services, of Indigenous Australians who are HIV positive.

3.1.3 The National HIV/AIDS Strategy 1996–97 to 1998–99

The third HIV/AIDS Strategy builds on the achievements of the second Strategy and takes account of the recommendations in the Feachem report. It recognises the sexual health context and the broader related communicable diseases context of HIV/AIDS and puts forward principles and processes to guide decision making on the best place way of responding to HIV/AIDS as it now is. The prime focus for minimising HIV transmission is gay and homosexually active men and Indigenous Australians, but the third Strategy is designed in such a way as to optimise the capacity to respond flexibly to any changes in HIV transmission. Injecting drug users will continue to be a high priority for education and prevention programs to control hepatitis C and to limit the possibilities of a future high rate of HIV occurrence among this group.

The third Strategy marks a change in the approach to HIV/AIDS and related issues in Indigenous Australian communities. It acknowledges that there is



considerable experience in sexual health matters in Indigenous communities, but the changing epidemiology of the disease suggests that there is a need to ensure that a comprehensive approach to education and prevention and treatment and care is adopted, building on the work already being done by Indigenous communities. This report expresses a commitment to the pursuit of the goals and approaches outlined in the third Strategy:

- to eliminate transmission of HIV;
- to minimise the personal and social impacts of HIV infection;
- a partnership approach between the community sector, government, the medical and scientific communities, and people living with HIV/AIDS and others affected by it;
- the centrality of involving affected communities in any response;
- encouraging a supportive social and legal environment to facilitate development of strategies to deal with HIV/AIDS;
- a harm-minimisation approach.

3.2 DEVELOPING THIS REPORT

There are several key documents and strategies in Aboriginal and Torres Strait Islander health policy which have guided the development of this report.

3.2.1 The National Aboriginal Health Strategy

In December 1987 the continuing poor state of Indigenous Australians' health led Commonwealth and State and Territory Ministers responsible for health and Aboriginal affairs to establish a Working Party to develop a national health strategy for Aboriginal people. The Working Party consisted of people with a vital interest in Aboriginal health, including representatives of Aboriginal health services and officials from Commonwealth and State and Territory health departments.

In its 1989 report the Working Party described the health status of Aboriginal people as completely deficient and well below that of any other group in Australia. The report, called the National Aboriginal Health Strategy, represented a milestone in Aboriginal policy in that it provided a culturally sensitive conceptual framework for dealing with Aboriginal health.

The 1994 evaluation of the National Aboriginal Health Strategy found that the Strategy was never effectively implemented. This failure was attributed to factors such as a lack of accountability for the Strategy's implementation across all levels of government and poor intersectoral collaboration. The evaluation reaffirmed the importance of the Strategy's principles and advocated a continuing commitment to the Strategy as a way of achieving equity in the health of Indigenous Australians. The Indigenous Australians' Sexual Health



Working Party endorses the principles of the National Aboriginal Health Strategy; they have underpinned the development of this report.

The National Aboriginal Health Strategy strongly advocated Aboriginal community control of and participation in health services as a means of ensuring that primary health care services were culturally appropriate and socially acceptable. This was seen to be essential if health services were to be responsive to changing local and regional needs. The following basic principles put forward in the National Aboriginal Health Strategy have guided the Indigenous Australians' Sexual Health Working Party in the development of this report:

- acceptance of Indigenous Australians' holistic view of health;
- recognition of the importance of local Indigenous community control of and participation in health care development and delivery;
- intersectoral collaboration.

This report will play a central role in the continuing development of health policy as it relates to Australia's Indigenous people.

3.2.2 The Royal Commission into Aboriginal Deaths in Custody

Between 1 January 1980 and 31 May 1989, 99 Indigenous Australians died in custodial care. In response to ongoing concern about the number of deaths in custody, the Royal Commission into Aboriginal Deaths in Custody was established in October 1987.

These deaths in custody and the actions surrounding them have left deep scars in the relationship between Indigenous Australians and the law enforcement and custodial systems in this country. The Royal Commission recommended action across a wide range of areas in an attempt to reduce, and minimise the impact of, contact between Aboriginal and Torres Strait Islander people and the judicial system. Improving Indigenous people's health was seen as integral to this, and the Royal Commission supported the implementation of the National Aboriginal Health Strategy. It also encouraged action by the custodial system to develop strategies that would reduce the risks of ill-treatment of Indigenous people in custody.

The Royal Commission made two recommendations that particularly affect this report:

- that the National Aboriginal Health Strategy be implemented;
- that strong relationships between correctional centres and Aboriginal community-controlled primary health care organisations be developed, to enable continuity of care.



3.2.3 The National Communicable Diseases Surveillance Strategy

The Chief Health Officers of the Commonwealth, States and Territories are developing a National Communicable Diseases Surveillance Strategy (Department of Health and Family Services 1996a). Its implementation will allow for better integration of current surveillance and for strong links between surveillance systems and policy development for the management of communicable diseases.

3.2.4 The National Hepatitis C Action Plan

The National Hepatitis C Action Plan, endorsed by the Australian Health Ministers Advisory Council in 1994, provides a strategic national approach to hepatitis C prevention and control. It calls for the continuing management of hepatitis C as a distinct infectious disease. There are, however, obvious overlaps between hepatitis C and HIV management, especially in the areas of surveillance, epidemiology and education, and these will be integrated with HIV/AIDS responses. The National Hepatitis C Action Plan will be reviewed in 1997 in consultation with affected communities and other relevant groups.

3.2.5 The National Drug Strategy

The National Drug Strategy provides the foundation for dealing with recreational drug use and HIV and hepatitis C prevention among injecting drug users through prevention, treatment and research. A number of initiatives aimed at both HIV and hepatitis C have been taken up under the Strategy. During the currency of the third National HIV/AIDS Strategy complementary initiatives will be further developed. It is envisaged that at the national level links will be explored in the areas of research, joint consideration of particular matters by both the ministerial advisory councils involved, and joint education and prevention activities in association with the States and Territories. The National Drug Strategy is currently being evaluated.

3.3 ROLES AND RESPONSIBILITIES

As is the case with the third National HIV/AIDS Strategy, the effectiveness of the response to this report and the Government's response to it depends on a clear understanding of roles and responsibilities and the cooperation of a wide range of organisations and individuals.

3.3.1 The Australian National Council on AIDS and Related Diseases and the Indigenous Australians' Sexual Health Working Party

The Australian National Council on AIDS was established to provide the Commonwealth Minister for Health with independent and expert advice on the implementation of the first two National HIV/AIDS Strategies; it was concerned principally with identifying national needs, objectives and priorities



and providing information to increase community understanding of HIV/AIDS. Under the third National Strategy ANCA's successor is the Australian National Council on AIDS and Related Diseases.

The role of ANCARD is based on that of its predecessor, but it will be expanded to include the provision of advice on those communicable diseases, such as STDs and hepatitis C, that have clear and direct links to HIV/AIDS. ANCARD will ensure that a mix of specific and integrated services is developed and maintained at an optimal level. It will also advise the Minister on overall implementation of the National HIV/AIDS Strategy 1996–97 to 1998–99.

As the Council of Australian Governments' reform process to simplify public health service delivery evolves, ANCARD will be working to ensure that the integrity of Australia's approach to HIV/AIDS is preserved. ANCARD's work will be assisted by a number of subcommittees and working parties, one of which is the Indigenous Australians' Sexual Health Working Party.

Until now, the role of the Indigenous Australians' Sexual Health Working Party has been to shape the direction and focus of this report, ensuring that Aboriginal and Torres Strait Islander communities have had the opportunity to contribute to sexual health policy and the development of programs at a national level. The Working Party has an important role in the future—to monitor implementation and provide advice to ANCARD on the progress of this report. The Working Party's role will continue to evolve, to reflect the principles and processes outlined in the National HIV/AIDS Strategy 1996–97 to 1998–99.

3.3.2 The National Aboriginal Community Controlled Health Organisation

NACCHO (the National Aboriginal Community Controlled Health Organisation) is the peak body representing Aboriginal community-controlled primary health care services. As the central policy body for primary health care services it has a crucial part to play in implementing the recommendations from this report.

At the State and Territory level there are also regional bodies that are affiliated with NACCHO and that represent Aboriginal and Torres Strait Islander health care services: the New South Wales Aboriginal Resource Co-operative Ltd; the Aboriginal Medical Services Alliance of the Northern Territory; the Queensland Aboriginal and Islander Health Forum; the South Australian Aboriginal Health Council; the Tasmanian Aboriginal Corporation; the Victorian Aboriginal Community Controlled Health Organisation; and the Western Australian Aboriginal Community Controlled Health Organisation.

The development and implementation of national, State and Territory and regional policies, programs and services for Indigenous Australians cannot proceed successfully without the involvement of NACCHO and the Aboriginal community-controlled health services.



3.3.3 Aboriginal community–controlled health services

The contributions of Aboriginal community–controlled health services will be fundamental to the success of implementing recommendations from this report. Many of the proposals put forward by the Working Party relate directly to strengthening the capacity of primary health care services to effectively diagnose and treat STDs and HIV.

The first Aboriginal community–controlled health service began in Redfern early in the 1970s in response to the mainstream services' inadequacy in dealing with the particular health needs of Aboriginal and Torres Strait Islander people. Since the Aboriginal Medical Service in Redfern was established many other such services have been established in all parts of the country. They take widely varying approaches to the delivery of health services within Aboriginal and Torres Strait Islander communities, and this variety is indicative of the services' ability to respond creatively to the circumstances of their local area.

Aboriginal community–controlled health services deliver a holistic range of primary health care services within a framework of self-determination. The services are very involved in community activities, depending on the needs of the local community and the funding available. They are often involved in the provision of health education, pre-test information and post-test counselling, antenatal care, nutrition programs, environmental health programs, mobile or outreach services, assisting with funerals, and sometimes specialised dental and medical services. Many of the services provide HIV and STD diagnosis, treatment, education and prevention programs and counselling as core activities.

Within these services Aboriginal and Torres Strait Islander health workers perform a great variety of tasks. Their responsibilities vary between communities and often encompass both a clinical role and community-focussed activities such as education and health promotion. As the main contact point for patient advocacy with Aboriginal health services and other services, Aboriginal and Torres Strait Islander health workers are crucial to the success of implementing recommendations from this report. They must be adequately resourced in terms of training, support and information.

3.3.4 The Australian Federation of AIDS Organisations

The Australian Federation of AIDS Organisations is the peak organisation representing HIV/AIDS-related community-based organisations, including State AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Intravenous League and the Scarlet Alliance. AFAO has a central role in maintaining effective participation in the third National HIV/AIDS Strategy by those communities most affected by HIV. It coordinates the efforts of community-based organisations, facilitates information exchange, and contributes to the development of national policies, programs and strategies.



AFAO's expertise in community development and peer education means that it can be a very useful resource for the Aboriginal community-controlled health sector in responding to HIV/AIDS and related diseases. AFAO has established the Indigenous Gay Men and Transgender Working Party and the Indigenous Gay Men and Transgender Project to address Indigenous sexual health issues. To varying degrees the State AIDS councils provide HIV prevention and care initiatives for people from Indigenous communities. Increased collaboration between these councils, AFAO, NACCHO and Indigenous community services will make implementation of recommendations from this report more effective.

3.3.5 The Commonwealth Government

The Department of Health and Family Services will continue to be the Commonwealth Government agency with overall responsibility for coordination, for Indigenous people, of the national response to sexual health and other related communicable diseases, with a focus on HIV prevention. The Aboriginal and Torres Strait Islander Commission and the Aboriginal and Torres Strait Islander Health Council also have vital roles to play in improving Indigenous Australians' health.

The Public Health Division

The Public Health Division of the Department of Health and Family Services will oversee a number of national initiatives, including the third National HIV/AIDS Strategy, the development of a national public health policy framework (the National Public Health Partnership) and the National Communicable Diseases Surveillance Strategy . The Division is also responsible for the National Drug Strategy and the National Hepatitis C Action Plan. In collaboration with the Office for Aboriginal and Torres Strait Islander Health Services it will oversee implementation of the response to this report.

The Office for Aboriginal and Torres Strait Islander Health Services

The Office for Aboriginal and Torres Strait Islander Health Services, within the Department of Health and Family Services, has assumed responsibility for providing funding to community-controlled organisations previously administered by the Aboriginal and Torres Strait Islander Commission. The Office has an important role in implementing the Government's overall Aboriginal health policy, including policy relating to sexual health. Policy implementation will take place through the network of funded Aboriginal health services and in the following ways:

- by ensuring that Aboriginal and Torres Strait Islander people participate fully in the development of appropriate programs in the area of sexual health;
- by facilitating the integration of specialist sexual health programs within the primary health care setting and ensuring that policy and administrative processes support this integration;



- by ensuring that matters associated with sexual health are dealt with through the joint planning forums currently being established in all States and Territories;
- by facilitating, through attention to training and human resource needs, the development of a primary care workforce skilled in sexual health management;
- by providing leadership and coordination, to facilitate the development of interventions aimed at reducing the incidence of specific health problems, particularly in relation to sexual health.

The National Aboriginal and Torres Strait Islander Health Council

The Commonwealth Government has also established the National Aboriginal and Torres Strait Islander Health Council. The Council provides advice to the Minister for Health and Family Services on strategies, priorities and policies to improve the health status of Aboriginal and Torres Strait Islander people. It has a central role in the development of Commonwealth health policy and will therefore be central to the implementation of this report's recommendations.

The Aboriginal and Torres Strait Islander Commission

The Aboriginal and Torres Strait Islander Commission continues to have a vital role in the provision of community infrastructure, such as adequate housing and community support facilities, and environmental health programs, such as disposal systems. Effective primary health care services are dependent on sound health system infrastructure and this inter-relationship is integral to meeting the health needs and improving the health status of Indigenous people. Links between the Commission and the Department of Health and Family Services in relation to coordination and planning of health programs have been formalised in a memorandum of understanding (1996 to 2001).

3.3.6 State and Territory governments

Under the third National HIV/AIDS Strategy, State and Territory governments are responsible for the following:

- establishing, convening and maintaining their own HIV/AIDS advisory forums with appropriate representation from all members of the partnership;
- establishing an appropriate public policy framework—dealing with, for example, housing, institutional care, adoption and school-based education—and legislation covering areas such as discrimination, prisons, homosexuality, drug use and the sex industry;
- investigating, analysing and monitoring the epidemiology of HIV within their jurisdictions;



- developing, delivering and evaluating a range of services—such as disease control, health promotion, and treatment and care—that reflect the prevalence of risk groups and the settings in which services are delivered;
- ensuring that resources are allocated broadly in line with the priorities identified in the Strategy;
- providing workforce infrastructure and training;
- measuring and reporting on the outputs and outcomes of the Strategy within their jurisdiction.

Some State and Territory governments have already developed Aboriginal and Torres Strait Islander HIV and STD strategies aimed at reducing STDs and preventing the transmission of HIV. It is important that each State and Territory moves towards mirroring the strategic framework offered in this report at all levels of health policy and service delivery, while taking account of local diversity and priorities.

State and Territory governments are also responsible, as partners, for implementation of the Aboriginal and Torres Strait Islander health framework agreements and for the work of State and Territory forums on Indigenous Australians' health.

Under the second National HIV/AIDS Strategy, State and Territory governments administered Aboriginal programs within the Matched Funding and Special Funding Programs. This role will evolve to reflect the strategic direction enunciated in the third National Strategy and developed through the joint planning forums. The forums will play a vital part in developing priorities and strategies for implementing recommendations from this report.

Under the second National HIV/AIDS Strategy, the States and Territories also moved to integrate HIV/AIDS programs with the prevention and control of STDs. In keeping with the findings of the Feachem evaluation, it is important to continue to integrate the elements of HIV/AIDS prevention and control with managing other STDs and related communicable diseases. The States and Territories are important in this process. Advisory committees at the State and Territory level, with representation of all members of the partnership, should have a key role in overseeing this process.

The Torres Strait and Northern Peninsula Health Council

The Torres Strait and Northern Peninsula Health Council was established in 1991 as an advisory council to the then Torres Strait Health Sector and the Queensland Minister for Health. The Council is an active and representative body with a history of working collaboratively with State and regional health authorities. It has 10 members, all of whom are representatives of community councils across the Torres Strait Islands and the far north of Cape York. The Torres Strait Regional Authority is also represented on the Council.



The Council's primary role has been to provide a community voice and facilitate communication between the community and government. It was an important contributor to the development of the Torres Strait Health Strategy (1993) and of an implementation plan for that Strategy (1995). The Council receives limited funding from the Queensland Government for administrative purposes.

3.3.8 The Commonwealth–State–Territory Government Forum

Under the second National HIV/AIDS Strategy the Intergovernmental Committee on AIDS (IGCA), as a standing committee of the Australian Health Ministers Advisory Council, provided a forum for regular Commonwealth–State–Territory liaison and coordination on policy, finance, programs and implementation of initiatives related to HIV/AIDS.

Under the third National Strategy, the composition and terms of reference of the IGCA (now called the Commonwealth–State–Territory Government Forum) will be revised to reflect the broader principles of the Strategy. This revision will occur in the context of the National Public Health Partnership, currently being developed.

The IGCA achieved a high degree of cooperation and understanding between governments on important aspects of HIV/AIDS policy and programs. It has been an important vehicle for moving HIV/AIDS programs in the States and Territories towards agreed national priorities and funding principles.

Arising from the agreed strategic approach of the National Public Health Partnership will be a number of forums for intergovernmental coordination and processes to involve the non-government sector in the public health activities generated through that Partnership, including in the areas of practice improvement, information development, national regulation and legislation, coordination and national strategies, research and development, workforce development, and resource allocation. The Commonwealth–State–Territory Government Forum will be accommodated within these arrangements as they are developed.

Moves to give the States and Territories greater responsibility and flexibility in program delivery, consistent with the Council of Australian Governments reforms, will require greater emphasis on the role of this Forum to ensure national consistency and coordination. As stated in the Feachem report, there is a need to develop better measures of outcomes and performance information. To this end, it has been proposed that a joint subcommittee of the Commonwealth–State–Territory Government Forum, ANCARD and community representatives be formed to develop indicators of relevance to HIV/AIDS and related matters. In addition, the States and Territories should be accountable to their communities for the funding and performance of services and should develop performance-information regimes for this purpose.



ANCARD and the Commonwealth–State–Territory Government Forum must continue to collaborate on important aspects of the management of HIV/AIDS and, increasingly, other STDs and related communicable diseases such as hepatitis C. This will be facilitated by cross-membership between the two bodies. ANCARD will advise on national policy matters and the Commonwealth–State–Territory Government Forum will make these policy matters operational.

3.3.9 Local government

Local government organisations play an important part in the national response to HIV/AIDS and related diseases by providing services such as community nursing and the disposal of waste such as needles and syringes. Local government also plays a crucial role in supporting community-based organisations and local education and prevention programs. The Working Party is aware of the problems associated with delivery of local government services to Aboriginal and Torres Strait Islander people, in particular those living in remote areas. It also notes the poorly developed local government infrastructure in many remote communities. As with all levels of government, services provided by local government must be delivered in a non-discriminatory fashion: there is a need to develop best-practise models within the local government sector, with continuing support and encouragement from the States and Territories.

3.3.10 Research, medical, scientific and health care professionals

Research, medical, scientific and health care professionals will continue to play an essential role in the delivery of treatment and care services and in training, research and policy advice. The Working Party notes that several professional organisations are taking important steps towards improving Indigenous Australians' sexual health. There is a need for further work to be done by these organisations to build effective partnerships with Indigenous people.

Organisations such as the Australian Medical Association, the Australian Nursing Federation and academic institutions should develop these partnerships through regular liaison, genuine two-way communication, and seminars, meetings and conferences. Continuing involvement in regional health initiatives and community forums will ensure that current concerns are raised within the primary health care sector and that options are explored through collaborative local approaches.

3.3.11 Parliamentary liaison groups

Committed non-partisan support for the National HIV/AIDS Strategy has characterised Australia's response to HIV/AIDS and has been instrumental in developing consensus on policy. The Commonwealth Parliamentary Liaison Group



has continued to ensure that the Commonwealth Parliament is regularly informed about the latest HIV-related developments and has provided a non-partisan forum for policy discussion. The Group is convened by the Minister for Health and Family Services.

All jurisdictions should develop a similar mechanism for fostering a non-partisan approach through building consensus on policy responses to matters relating to HIV and other public health problems such as hepatitis C. ANCARD will report annually on the success or otherwise of these initiatives.

3.3.12 Local organisations

The network of local organisations or informal groups in some Aboriginal and Torres Strait Islander communities acts as a support, educational and information-sharing resource. A different range of local organisations—such as youth groups, women’s groups and sporting organisations—may have a role to play in HIV/AIDS and STD education and prevention work, and in the care and support of people living with HIV/AIDS in some Aboriginal and Torres Strait Islander communities.

3.4 BUILDING EFFECTIVE PARTNERSHIPS

The partnership approach has been fundamental to Australia’s HIV policy since the beginning of organised action to combat the virus. The partnership is an effective, cooperative effort between all levels of government, community organisations, medical and scientific communities, people living with HIV/AIDS, and other affected people, all working together to control the spread of HIV and to minimise the social and personal impacts of the disease.

The partnership is based on a commitment to consultation and joint decision making in all aspects of the response. The Feachem report noted that there are no shortcuts to a comprehensive policy framework that involves the affected communities and ensures high-quality professional participation. Maintaining the partnership can be work for all participants, but it is a relationship worth sustaining.

The Working Party notes that the third National HIV/AIDS Strategy does not see the partnership role of community organisations as being a passive one, involving mere consultation after decisions have been made. Rather, the Strategy emphasises and champions community involvement in every level of decision making and policy formulation. The Working Party considers that extending this partnership philosophy to encompass Aboriginal and Torres Strait Islander people and organisations is fundamental to the process of dealing with sexual health in the Indigenous Australian community.

The National Aboriginal Health Strategy identified the advances in health and community development in Aboriginal and Torres Strait Islander communities that effective intersectoral collaboration would make possible. Most of the



Working Party's consultations and the submissions it received saw lack of partnerships as the major cause for the lack of success of previous strategies. There was a strong view that too many strategies, programs, policies and services had been established without community input or control. A partnership needs to exist between all levels of government, peak bodies and service providers as well as between community-controlled and mainstream health organisations. Several submissions were concerned about the need to clearly define the roles and responsibilities of all players.

Some submissions stressed the need for regional planning; others stressed the need for more coordination across programs within Commonwealth Government departments (such as the Department of Health and Family Services). Cross-border issues were seen as greatly increasing the need for coordination.

The Working Party notes a number of important mechanisms and alliances that have the capacity to greatly enhance the implementation of recommendations from this report:

- the role of the Australian Health Ministers Advisory Council;
- the role of the Torres Strait Treaty Joint Advisory Council;
- cooperation between State and Territory governments to develop cross-border approaches;
- strengthening the alliance between NACCHO, AFAO and the National Association of People living with HIV/AIDS;
- strengthening the alliance between ANCARD and the National Aboriginal and Torres Strait Islander Health Council.

3.4.1 The Australian Health Ministers Advisory Council

As the body that provides advice to all Australian health ministers, the Australian Health Ministers Advisory Council can play a big part in taking up the matters discussed in this report that require national commitment. The Working Party notes that changes to public health administration in Australia will necessitate improved collaboration between all players. The following are priorities identified during the consultation process that might be given further consideration by the Council:

- the need to closely monitor international borders, in particular the border between the Torres Strait Islands and Papua New Guinea. This is especially important because of the high rate of cross-border migration and travel, the poor level of health infrastructure in Papua New Guinea, and the potentially high rate of HIV infection and related communicable diseases in Papua New Guinea;
- the development by the States and Territories of specific Aboriginal and Torres Strait Islander sexual health strategies within the broader framework established by this report.



- the establishment of processes for collaboration on internal cross-border matters;
- representation of Indigenous Australians on all State and Territory HIV/AIDS advisory bodies.

These priorities should be pursued in collaboration with the Indigenous Australians' Sexual Health Working Party and the National Aboriginal and Torres Strait Islander Health Council.

3.4.2 The Torres Strait Treaty Joint Advisory Council

The Torres Strait Treaty was signed by the Prime Ministers and Foreign Ministers of Australia and Papua New Guinea on 18 December 1978. The Treaty concerns sovereignty and maritime boundaries in the area between the two countries. It recognises the importance of protecting the traditional way of life and the livelihood of Torres Strait Islanders and Papua New Guineans living in the coastal area adjacent to Torres Strait, and it sets out protocols for the conduct of the relationship between Papua New Guinea and Australia in the Torres Strait region. Implementation of the Treaty is monitored by the Joint Advisory Council.

There are two main border-related health concerns:

- the possible introduction of communicable diseases resulting from the free movement of traditional visitors between communities in the Torres Strait Islands and Papua New Guinea;
- pressures on Australian health care facilities from Papua New Guinea's traditional inhabitants as a result of limited access to health service facilities and poor standards of care in the Western Province of Papua New Guinea.

AusAID (the Australian Agency for International Development), the Department of Foreign Affairs and Trade and the Department of Health and Family Services are the Commonwealth Government bodies responsible for supporting Australia's international response to HIV/AIDS. There is an urgent need to strengthen existing mechanisms for cross-border communication and cooperation and regional activities in primary health care to improve the sexual health of the Indigenous communities of both countries.

3.4.3 State and Territory governments

State and Territory governments should work cooperatively to develop responses to cross-border strategies. Disease does not respect State and Territory borders. Given the high mobility of some sections of the Aboriginal and Torres Strait Islander community, cooperative mechanisms are needed. In particular, these mechanisms need to provide the basis for ensuring continuing treatment and care of those diagnosed with STDs or HIV. Consultations have identified the need for cross-border work to occur across all State and Territory borders.



3.4.4 Strengthening the alliances

NACCHO, AFAO and the National Association of People Living with HIV/AIDS

NACCHO and AFAO represent Aboriginal community-controlled health services and AIDS organisations respectively and an effective and close alliance between these two organisations is essential. At the local level, there is an obvious need for better relationships between AIDS organisations and Aboriginal community-controlled health services: a close national partnership between NACCHO and AFAO could encourage and oversee the development of these relationships.

Both organisations can also play an important part in each other's policy-development processes: NACCHO can bring substantial expertise in health service delivery to Aboriginal and Torres Strait Islander communities while AFAO has much to offer NACCHO in terms of expertise in the prevention of HIV and in treatment and care for people living with HIV/AIDS.

The Working Party also sees the need for strengthening the alliance between the National Association of People living with HIV/AIDS and NACCHO. NACCHO offers an avenue for NAPWA to effectively reach Aboriginal and Torres Strait Islander people living with HIV/AIDS. It can also provide information on the adequacy of current health service delivery arrangements for Indigenous Australians. As the national body representing people living with HIV/AIDS, NAPWA can help NACCHO, and its member services, to more effectively meet the treatment and care needs of people living with HIV/AIDS.

ANCARD and the Aboriginal and Torres Strait Islander Health Council

As the chief ministerial advisory bodies on AIDS and related diseases and on Aboriginal and Torres Strait Islander health, both ANCARD (through this Working Party) and the Aboriginal and Torres Strait Islander Health Council have key roles to play in overseeing the implementation of this report. ANCARD has substantially increased its capacity to advise on Aboriginal and Torres Strait Islander matters by appointing several Indigenous members. The Working Party considers that regular coordination between the two Councils will strengthen the capacity of both to provide high-quality advice to the Minister.

3.5 HEALTH SECTOR REFORM

3.5.1 The Aboriginal and Torres Strait Islander health framework agreements

The most important policy partnership that will guide and monitor Aboriginal and Torres Strait Islander health is the Aboriginal and Torres Strait Islander health framework agreements. The Commonwealth Government has been



negotiating these agreements with all State and Territory governments. The agreements, which are underpinned and informed by the National Aboriginal Health Strategy, have been signed by all States except Tasmania and the Northern Territory.

The health framework agreements are designed to improve cooperation and collaboration between all interested parties, including the Aboriginal and Torres Strait Islander Commission and Aboriginal and Torres Strait Islander community-controlled health organisations. Additionally, the agreements will be linked to the new arrangements for public health policy, program administration and health financing to ensure that Aboriginal and Torres Strait Islander health outcomes and performance measures are a priority.

The agreements provide for the formation of a State or Territory forum with three main responsibilities:

- to decide on how regional plans will be developed—the plans are intended to cover all health care service provision matters and to identify deficiencies and opportunities in health care provision and priorities for improving health services;
- to inform policies and decision making in relation to existing and new mainstream and Aboriginal and Torres Strait Islander-specific primary health care services;
- to evaluate the implementation of the agreement in the State or Territory.

The State and Territory forums will also provide an opportunity for greater information exchange and allow the process to be directed by Aboriginal and Torres Strait Islander people's needs and thinking. The forums contain representatives of the following bodies:

- the Commonwealth Department of Health and Family Services
- the Aboriginal and Torres Strait Islander Commission
- the State or Territory health authority
- State or Territory-based NACCHO affiliates.

3.5.2 Public health agreements

In June 1996 the Council of Australian Governments agreed to a reform agenda designed to fundamentally realign Commonwealth and State and Territory activity in health and community services. New arrangements for public health policy, programs and financing between the two levels of government will be developed in the coming years. These reforms propose that Commonwealth-State funding agreements for HIV/AIDS be consolidated with other public health programs into one public health agreement for each State and Territory. Among the aims of the reforms are improving health outcomes for people, making health service infrastructure more flexible and less



complex, providing incentives for preventive health and cost-effective care, and ensuring quality care that is responsive to people's needs.

The Special Funding Program was established under the second National HIV/AIDS Strategy to improve STD and HIV/AIDS services for Indigenous Australian communities. Funds are offered to the States and Territories according to the size of their Indigenous populations. In recognition of the need for meaningful community involvement and participation in the development and delivery of services for Indigenous people, the States and Territories are required to consult with their Indigenous population as part of the Special Funding Program guidelines.

The Working Party on Indigenous Australians' Sexual Health recommends that HIV/AIDS funds from the Special Funding Program not be rolled into the Public Health Agreements. Reducing the rates of STD infection and transmission of HIV among Indigenous Australians will require sustained Commonwealth leadership and an ability to press for more collaborative approaches, from both State and Territory governments and the community-controlled sector. Funding-delivery systems should encourage collaboration between sectors rather than competition. It is crucial for the Commonwealth to continue to set and maintain a clear direction. Retaining funding and leadership responsibility will facilitate the delivery of a sustainable strategy to redress the problem of STDs and HIV in Australia's Indigenous communities. Funding capacity at the national level, to respond rapidly to changes in the epidemiology of HIV, STDs and related blood-borne viruses, should be maintained.

In light of its consultations and the submissions it received, the Working Party proposes that Commonwealth funds be used to encourage cooperative approaches between different sectors to Indigenous sexual health. The funds could also be used to facilitate cross-border approaches such as the Tri-State Project piloted in Central Australia.

The Commonwealth and the States and Territories are also working cooperatively to meet the needs of groups requiring higher levels of care more effectively than may be happening under current arrangements. Coordinated care trials are being introduced to test whether coordinating care will result in improved client health and well-being within current resource levels. The trials are expected to contribute to the development of improved services for people with complex health needs, including people with AIDS.



Prevention

4.1 INTRODUCTION

The prevention of the spread of blood-borne and other sexually transmitted diseases, including HIV/AIDS, is a key focus in improving the sexual health of Aboriginal and Torres Strait Islander people. The Working Party stresses that prevention in Aboriginal and Torres Strait Islander communities will require fundamental change at a broader level than individual behaviour. In particular, it is important to note that for the non-Indigenous community, infrastructure that is taken for granted in the mainstream arena, such as effective primary health care, is not always available. Access to primary health care is one of the key areas that will need to be addressed if sexual health is to be improved.

The Working Party also wants to stress that, in the Indigenous context, prevention will require the implementation of a comprehensive strategy. It will not be sufficient, for example, just to run campaigns which teach people about safe sex. Nor will it do to just concentrate on the free provision of condoms. It will only be when all elements of the strategy are implemented, in a cohesive manner, that there will be a possibility of lasting change.

The Working Party notes the strategic importance to HIV prevention of diagnosing and treating STDs. The link between infection with syphilis and an increased risk of HIV transmission is now well recognised. Recent research in Africa has demonstrated a clear relationship between STD prevalence and the transmission of HIV (Grosskurth et al. 1995). This study, in Tanzania, used randomised controlled trials to examine the impact of improved treatment of STDs on rates of HIV infection. It found that improved STD treatment reduced HIV incidence by about 40 per cent in the study population. The results reinforce the concept that effective interventions focussed on STDs should be an essential element of HIV prevention in those regions of Australia in which STD rates are elevated in comparison with the general population.

Further, preliminary analysis of a study of STD transmission in the Northern Territory suggests that the main determinant of high rates of STD infection in Aboriginal and Torres Strait Islander communities is poor access to treatment, not the number of sexual partners (Bowden & Fairley 1996). On the basis of this, it is now safe to assume that strategies to reduce the duration of STD infection, through appropriate primary health care, will have a substantial effect on the rates of STDs in Aboriginal and Torres Strait Islander communities. It can also be concluded that behaviour-modification strategies

on their own will have limited effect and that fundamental change at a broader level is necessary. Education programs must be developed in conjunction with improving access to appropriate diagnosis and treatment of STDs.

Infrastructure that is taken for granted in mainstream Australia, such as effective primary health care, is not always available to the Indigenous community. Access to primary health care is essential if Indigenous Australians' sexual health is to improve. Education programs are part of a comprehensive primary health care approach.

From its consultations, the Working Party has identified six elements that are crucial for any prevention strategy:

- the provision of high-quality, timely primary health care, particularly designed to reduce rates of STDs in Indigenous communities;
- education programs that not only provide information on reducing risks but also support broader behaviour change within communities;
- the provision of equipment that helps people avoid risks—condoms, clean needles, and single-use equipment for ceremonial practices, for example;
- an environment free of discrimination on the basis of sexual practice, race or drug use behaviour;
- a legislative framework that facilitates, rather than inhibits, the effective implementation of the strategy;
- the development and maintenance of high-quality health information systems that provide communities with timely information on the changing profile of HIV and its related risk factors.

The third National HIV/AIDS Strategy's objectives for education and prevention are also relevant to this report:

- to reduce the overall numbers of HIV infections in Australia by reducing the level of HIV infections in established epidemics, minimising the level of infections in emerging epidemics, monitoring and responding to any changes in patterns of HIV infection, and maintaining our success in preventing the epidemic;
- to reduce the transmission of hepatitis C and sexually transmissible diseases within the context of this report, focussing on the relationship between HIV/AIDS, hepatitis C and sexually transmissible diseases generally;
- to reduce the personal impacts of HIV infection, sexually transmissible diseases and related communicable diseases, including reducing levels of discrimination, prejudice and violence directed at people infected with and affected by these diseases;



- to develop community capacity to respond effectively to epidemics of HIV and hepatitis C in an appropriate fashion;
- to maintain awareness of HIV/AIDS and related sexually transmissible and communicable disease problems within the Australian community and to integrate our national responses to these diseases within an appropriate time frame (Department of Health and Family Services 1996b, pp. 38, 39).

During the Working Party's consultation process, a number of important principles that should be considered in implementing a prevention strategy emerged:

- the need for community involvement, control and commitment at all stages of program design, delivery and evaluation;
- the need for prevention strategies to take into account the diversity of cultural practices and circumstances of Aboriginal and Torres Strait Islander people;
- the development of capacity at a local level to allow concerns and interests to be accommodated in a way that acknowledges this cultural diversity;
- the integration, within a primary health care framework, of educational, population health and clinical approaches to sexual health;
- the provision of programs that meet the specific needs of both Aboriginal and Torres Strait Islander men and women in accordance with local cultural practices, such as by providing both female and male workers and educators;
- the integration of sexual health information into other health and community programs and settings, such as alcohol and drug services, schools, employment programs, and correctional facilities.

All these principles are integral to the success of a prevention strategy.

4.2 THE ROLE OF THE PRIMARY HEALTH CARE SECTOR

Primary health care agencies have a central role in improving the sexual health of Aboriginal and Torres Strait Islander people, so it is essential to focus on increasing the capacity of the primary health care sector.

In the Aboriginal and Torres Strait Islander context, 'primary health care' refers to a community-based process that enables local communities to actively participate in the design, and delivery, of services. Primary health care has the capacity to be responsive to community needs and covers a wide range of activities, such as the following:



- promotion of the well-being of individuals through the provision of clinical care, drugs, specialist services, allied health care services, emotional health services, and programs directed at the specific health needs of women, men and children;
- the support of people with disabilities and chronic illness, to enable them to keep living with their families;
- health promotion, research, screening, internal program evaluation, and other public health activities.

It is important for people living with HIV/AIDS, hepatitis C and STDs to be involved in the development and implementation of prevention strategies. This not only has the benefit of promoting their role as active agents in strategies to address sexual health issues, but will ensure that these strategies are most likely to have an impact.

Aboriginal community-controlled health services are committed to a holistic approach to health care. In the sexual health context, this means that health care encompasses primary medical care, population health programs designed to reduce STDs and HIV, and education to minimise the risk of infection and support behaviour change. It is also necessary to see primary health care delivery as just one of the elements in a broader process of community development.

Rates of gonorrhoea infection among males were cut by two-thirds between 1985 and 1995 in three Kimberly shires that had Aboriginal community-controlled health services. There was no significant decline in the shires without these services. Further data suggest that the reason for the reduction is targeting of individuals with frequent STD infections, an approach dependent on local knowledge and effective counselling for behavioural change.

The promotion of strategic partnerships between the primary health care sector and mainstream specialist organisations (such as AIDS councils, public health agencies and specialist prevention and treatment services) will allow for more effective direction of local resources into holistic health care. Non-primary care agencies and services also have an important part to play in the development of a comprehensive framework for prevention.

A number of other important questions need to be addressed in the primary health care context because of the need for community control and the need for sensitivity and respect.

The Working Party notes that there appears to be a strong relationship between abuse of alcohol and a reduction in commitment to risk-minimising behaviours. Substance misuse programs and sexual health programs must recognise and respond to this. The relationship between injecting drug use and the transmission of HIV and related diseases, including hepatitis C, is also of great concern.



The National Drug Strategy and the Aboriginal Substance Misuse Program are currently under review—the findings of these reviews could influence approaches to sexual health programs.

Sexual abuse is a difficult and complex area. But it was one of the most pressing concerns expressed in Working Party's consultations and other forums. Primary health care services should consider ways to address sexual abuse and related social problems in their planning and development processes. Collaboration with specialist organisations would be appropriate.

4.3 IMPROVING THE DIAGNOSIS AND TREATMENT OF STDs

Where integrated programs are being run by primary health care services, successes in reducing the rate of STDs have been demonstrated. The Kimberley Aboriginal Medical Service's Council has shown that the presence of primary health care facilities has had a great impact on rates of STDs, particularly gonorrhoea. In regions where there is a community-controlled Aboriginal health service rates of gonorrhoea have been cut by up to 70 per cent.

Nganampa Health Council has demonstrated that effective public health models incorporated in the primary health care setting are integral to STD prevention. Nganampa's program, which has the full support of the community, has reduced the prevalence of syphilis in the region from an estimated 20 per cent in 1985 to 1.7 per cent in 1996.

Access to primary care services must be extended to those communities without adequate facilities. For the diagnosis and treatment of STDs, existing primary health care services can be strengthened in a number of ways:

- ensuring that treatment is based on the best, evidence-based practice, including the development and use of clinical care guidelines for diagnosis and management;
- ensuring that clinical care guidelines are developed by those who use them and that they are relevant to the particular circumstances of local areas;
- facilitating appropriate use of new non-invasive diagnostic technologies that encourage people to go along and be tested;
- using new treatment regimes that simplify treatment, such as azithromycin for the treatment of donovanosis;
- developing screening strategies, where appropriate, in accordance with the principles explained in Section 4.3.2;
- developing and maintaining appropriate mechanisms for follow-up of an often mobile population—for example, client-recall systems;



- developing and maintaining quality health information systems that provide communities with timely information on the changing profile of HIV and its related risk factors;
- facilitating the continuing development of and commitment to confidentiality processes within services;
- developing culturally relevant pre-test information and post-test counselling guidelines;
- providing training for Aboriginal health workers in counselling, encompassing the broad range of relevant skills—for example, death, dying, grief, loss, family relationships, sexuality, drugs and alcohol.

The Sexual Health Program of Far North Queensland has developed the flow-chart management of sexually transmissible diseases in isolated community health centres and clinics, which outlines client management, protocols for management of specific STDs, treatment codes, and steps for clinical record management.

4.3.1 Advances in STD screening technology and treatment

Polymerase chain reaction tests

Advances in STD detection methods have created a much more efficient and effective environment for the diagnosis of STDs in Indigenous Australian communities. Polymerase chain reaction (PCR) urine testing has been trialled in a number of locations since its commercial release. This new technology, involving DNA amplification, is proving effective in diagnosing chlamydia and gonorrhoea, two STDs frequently encountered in remote communities. PCR amplification technology is also being developed for the detection of donovanosis and herpes and is expected to be available for use in 1998.

The Tri-State Project, in conjunction with Nganampa Health Council and Congress, introduced the first void urine tests for screening for gonorrhoea and chlamydia. Tri-State also trialled azithromycin in the treatment of donovanosis.

PCR technology offers some important benefits in detecting STDs, particularly in rural and remote settings. Compared with other technology, it is far less dependent on the availability of highly skilled clinicians and is less affected by climate and transport times. PCR tests are also much less invasive. They enable the use of urine-testing, which has been particularly helpful in the traditionally difficult area of male sexual health. The use of tampons as a diagnostic medium has been trialled in some areas and preliminary results look promising. Some Indigenous women in some regions are reported to be more comfortable with the procedure (because of its ease and simplicity) and



compliance rates for testing have risen dramatically as a result. Further study is, however, required in connection with testing sensitivity and possible flow-on effects, such as reduced attendance by women for cervical cancer screening because of the perception that this is no longer important.

Eight Ways to Beat HIV is a comprehensive strategy for STD control and HIV prevention in remote Aboriginal communities. The program, which provides risk-reduction education and pre-test information and post-test counselling in Pitjantjatjara, has introduced urine testing for STDs, confidential HIV tests, and a 'safe ceremonies' project run by senior men.

Continuing research into the use of PCR technology will be the key to its effective use in STD screening. At present, PCR testing procedures are not included in the Pathology Services Table in the Medicare Benefits Schedule. A Working Party of the Australian Health Technology Advisory Committee is reviewing the clinical value, impact and cost-effectiveness of DNA/RNA (deoxyribonucleic acid/ribonucleic acid) amplification testing, including PCR testing and related technologies; and it expects to report to the Australian Health Technology Advisory Committee in April 1997. The results of this review will inform funding decisions, relating to DNA/RNA amplification technologies.

The cost implications of PCR technology are not apparent at this stage, but costs will probably not be significant in comparison with the financial and social costs arising from HIV/AIDS in Aboriginal communities. The Commonwealth needs to ensure that these matters are dealt with in a timely manner, in order to promote, resource and enhance Indigenous sexual health care strategies.

As with the introduction of any new technology or testing regime, the short- and long-term effectiveness of PCR testing can be ensured only through the allocation of adequate training resources for those using the procedure.

In particular, training must be delivered to Aboriginal and Torres Strait Islander health workers. Apart from detailing the components of the screening and treatment process, this training should contextualise the role of PCR testing in the context of the policies and local strategies that apply to health workers. It is not sufficient to simply raise the clinical understanding of health workers. Training should equip health workers with the ability to explain new diagnostic methods to clients as well as any benefits and drawbacks. In this way PCR testing can be a useful tool in prevention and education. The Commonwealth should ensure that Indigenous health workers receive suitable training in the benefits of PCR technology for the diagnosis of STDs.

Treatment with azithromycin

Studies of azithromycin given as a once-weekly supervised dose show it is highly effective in the treatment of donovanosis. This is a marked



improvement on previous therapies, which required long-term treatment and were attended by compliance difficulties. Treatment with azithromycin has the capacity to lower the incidence of one of the main ulcerative STDs and therefore greatly reduce the potential for HIV transmission.

This is one example of improvements in treatment regimes for STDs. It demonstrates that there needs to be continual monitoring and dissemination of information about innovations in therapies.

The Commonwealth should take a lead role in disseminating to the primary health care sector new information on improved diagnostic and treatment methods for STDs.

4.3.2 The role of STD screening

Screening programs in Aboriginal and Torres Strait Islander communities have often been associated with research into the prevalence of conditions, with no commitment to attendant treatment needs. There has also been little community involvement in or control over screening programs. In recent years, however, positive results have been achieved by encouraging informed community participation in the development and implementation of programs. Nganampa Health Council's screening program is an example of a successful intervention.

Opportunistic screening has also been used by primary health care agencies, as a part of well people's checks. Until very recently, men have had poor levels of attendance for health check-ups. The less invasive methods of STD screening just outlined, coupled with strategies to increase the numbers of male Aboriginal health workers, may enhance access to these programs for Aboriginal and Torres Strait Islander men.

Screening is defined as 'the examination of asymptomatic people to classify them as likely, or unlikely, to have the disease which is the object of screening' (Mitchell & Irwig, 1991). Most diseases are diagnosed and treated when a person with symptoms attends a primary health care setting. In many instances, the disease may be well advanced by the time a person seeks treatment, particularly in remote communities, where access to primary health care is difficult.

Efficient and non-invasive diagnoses for STDs and effective treatment regimes have increased the potential for active case finding, or screening, which can offer substantial benefits for individuals and the whole community. Mitchell and Irwig (1991) propose that four criteria need to be met before undertaking a program of active case finding:

- The disease must constitute a substantial health problem in the population to be screened.



- The screening test should accurately identify a high proportion of persons with early stages of the disease.
- The detection and management of the disease in its preclinical stage should result in an improved outcome.
- The screening test should be safe, acceptable to the population, easy to use, and of relatively low cost.

Scrimgeour (1996) suggests that the following criteria must be added for any screening process involving Aboriginal and Torres Strait Islander people:

- There must be sufficient planning and resources to adequately follow up diagnoses of STDs with appropriate treatment.
- Aboriginal and Torres Strait Islander people must be sure that the benefits of the program outweigh the intrusion and surveillance.

Community participation in the development of screening strategies is vital. The questions to be answered are: How frequently should screening occur? In what context? And by whom? Screening also needs to be linked to mechanisms that provide local communities and participating organisations with feedback so that the screening is conducted as part of a holistic primary health care approach. Screening strategies also need to be flexible, to accommodate changes in regional and local disease profiles.

The Working Party emphasises the need for screening activities to be adequately resourced. In promoting a primary care approach to STD prevention, this will mean resourcing the primary health care sector to conduct screening programs, to develop and maintain health information systems, and to have access to relevant public health experts. The primary care sector should also be resourced to provide clinical care and education, so that screening activities are properly integrated with the other components of a prevention strategy.

The Working Party does not advocate the comprehensive screening of Aboriginal and Torres Strait Islander people for HIV antibodies, based on the above criteria. Issues around HIV testing are discussed further in section 5.2.2.

4.3.3 Reducing the risk of disease transmission in the primary health care setting

The Working Party recommends that all Aboriginal health services be resourced to develop protocols for reducing the risk of transmission of HIV and related diseases. In particular, organisations should ensure that they have protocols for 'needle stick' injury, handling of blood and body fluid spills, and infection control for medical procedures. The Commonwealth and State and Territory governments should ensure that information on best practice in these areas is collated and regularly distributed to services.



There is also a pressing need, particularly for services in rural and remote areas, to be fully informed about the safe disposal of ‘sharps’ and other potentially infectious waste. The State forums being established under the health framework agreements offer one avenue for State and Territory governments to work cooperatively with Aboriginal community-controlled health services in this regard.

4.3.4 Informed consent

It is vital that people are able to make an informed choice about their involvement in any form of screening program. Confidentiality is also extremely important: an individual must know that the results of any tests will not be used inappropriately.

The Working Party notes, with concern, that STD screening may be done as a routine part of antenatal care, without the consent of the woman involved. This practice must stop: it has the potential to deter women both from seeking crucial antenatal care and from freely seeking STD diagnosis. Testing for STDs during pregnancy is important in order to minimise the health consequences to the unborn child, but the Working Party stresses that this testing should take place with the informed consent of the woman. The Commonwealth and States and Territories should take the lead in ending testing for STDs without informed consent, particularly during antenatal care.

4.4 COLLABORATION AND REGIONAL PLANNING

Strategies to improve collaboration between the different health sectors are necessary for four main reasons:

- to provide a consistent approach to prevention;
- for continuity in the clinical care of STDs;
- for improved treatment as a result of the development of closer working relationships between primary care agencies and specialist services;
- for the development of regional prevention strategies.

Such collaboration can be developed through the partnership mechanisms described in Chapter 3. Of particular importance will be the joint planning forums being established under the health framework agreements. In addition, the development of close ties between national bodies such as NACCHO and AFAO can encourage collaboration at a local level.

The diverse needs of communities across the country mean that planning must be done at a regional level, with local-level responses. Regional strategies should deal with prevention and treatment and mechanisms for local collaboration. Local-level responses can then deal with identified priorities such as waste disposal, harm minimisation, education and prevention, and STD screening and treatment as appropriate.



The Working Party notes the need to develop and implement regional and local population health strategies to tackle STDs in a manner that encourages collaboration between primary health care services and public health agencies. This can best be achieved through links with State and Territory joint planning forums, which have responsibility for determining how regional plans will be developed.

4.5 EDUCATION STRATEGIES

Education strategies are an essential part of a comprehensive primary health care approach to improving the sexual health of Indigenous Australians. Among the purposes of education strategies are the following:

- to provide information on ways to reduce the risk of transmission of HIV/AIDS, STDs, hepatitis C and other blood-borne viruses;
- to help create an environment in which people feel they can discuss sexual health and that will support behaviour change;
- to reduce fear and discrimination;
- to encourage voluntary presentation to services for diagnosis and treatment.

4.5.1 The principles of education strategies

A number of important principles for the development and implementation of education strategies were identified through the consultation process:

- Aboriginal and Torres Strait Islander people must be involved in all stages of program development—with a particular emphasis on the agreement and involvement of elders and other community leaders.
- Local health and social issues (such as substance use) should be incorporated in educational programs and activities.
- Evaluation strategies designed to gauge the effectiveness of education and prevention initiatives should be incorporated in program design and should focus on whether programs have met identified community priorities and needs.
- Health professionals and community members should be involved in developing performance indicators for education initiatives.
- Program content and delivery must be non-judgmental and directed at the specific needs of individuals and groups within the community—for example, young people, homosexually active men, prisoners and substance users.
- There should be a focus on matters particularly affecting young people.



- All members of the community need to have a good understanding of sexual health and of how to minimise risk.
- Initiatives should not be restricted to the health sector or the health environment; rather, they should be integrated with other community functions and locations (such as sporting activities, the shops and pubs).

Aboriginal youth camps have been successfully run across the Greater Murray region. They aim to promote self-esteem and identity as an Aboriginal person, cultural awareness, spirituality, a healthy lifestyle, and the caring and sharing of culture. Young people's evaluations have been very positive and there have been requests for additional camps that last longer and involve an Aboriginal HIV- positive person.

Education is an essential component of clinical practice, particularly when it comes to behaviour change. The combination of clinical care and education can make client service more effective, enhance knowledge, and encourage risk-reducing behaviours.

Torres Strait Islander health workers provide culturally appropriate services in the area of sexual health, including education, prevention, treatment and contact tracing throughout the 15 outer islands, Thursday Island and the northern peninsula area.

An individual or community's ability to change behaviour in order to enhance health requires a supportive environment. Behaviour change can be strongly inhibited by poverty, personal and community trauma, poor access to educational opportunities, high rates of unemployment, high rates of other illnesses and health problems, low self-esteem, and other socio-economic factors. All of these factors diminish the capacity of individuals and communities to respond effectively to the threats posed by HIV and other sexual health problems and hepatitis C. This must be taken into account in the researching and implementation of education initiatives designed to improve sexual health.

Little research has been done into how behaviour is influenced and changed in Aboriginal and Torres Strait Islander communities. Such research is necessary, to inform the development of future responses.

The Working Party notes the importance of ensuring that education strategies embrace the entire community, not just those at high risk of HIV, STDs and related diseases such as hepatitis C. For two reasons, education strategies also need to promote access to appropriate and timely care and support services:

- Specific prevention initiatives aimed at high-risk groups (such as gay men or injecting drug users) require broad community support. This support can be generated if the community has a good understanding of



HIV/AIDS and other matters connected with sexual health, including prevention strategies.

- Family members and others in the community can play an important part in supporting behaviour change.

Sexual health education involves sensitive and intimate aspects of people's lives. This often results in a situation where there is a good deal of 'shame' attached to the subject, which makes the discussion awkward and uncomfortable.

The fear and uncertainty that give rise to discrimination can be confronted only by promoting healthy relationships and mutual respect and trust. The involvement of HIV-positive community members in prevention strategies is essential and should be supported by appropriate funding and resource allocations. A national education program should be developed in conjunction with innovative care and support initiatives; the program should incorporate action to redress the serious discrimination and attitudinal difficulties raised at the 'Anwernekenhe' Conference at Hamilton Downs in the Northern Territory.

4.5.2 Diversity

Consultations revealed a need to maintain and enhance several features of existing education and prevention programs, including the development of both generic and localised Indigenous education resources. They also confirmed that education activities must be appropriate to the needs of the individual and the community. To do this, education approaches must be closely integrated with other primary health care functions.

Programs should be designed and developed within a local community context, using local concepts and learning strategies. This is possible only if local Indigenous people are involved in all stages of program development and delivery. It is important to retain existing systems and mechanisms that are recognised by community members and are strongly embedded in cultural structures and communication networks: education programs should work within these structures and networks.

Biripi Aboriginal Medical Service is running 'Getting your Ls', which is directed at people outside the usual educational system. Courses held in 1996 had high participation rates. The courses, in Taree, combine formal driving tuition with education on topics such as relationships, hepatitis, sex and STDs.

In keeping with the principle of educating all community members, specific education programs for people of all ages and situations should be developed—for parents, for young people, for elders, and so on. Initiatives should not be restricted to the mainstream; they should be integrated and



provided by Aboriginal community–controlled health organisations within the primary health care context. Aboriginal community–controlled health organisations need to be adequately resourced for this.

Continued emphasis on community-focussed education initiatives should be resourced and coordinated at a regional level. This includes the delivery of health promotion and education programs in both health and non-health settings. The Working Party’s consultations and the submissions it received suggested that sporting events, health expos, school projects, parent groups, and other such avenues are very useful for delivering sexual health messages.

The HIV/AIDS education play *No Prejudices*, developed by the Kimberley Aboriginal Medical Service’s Council, is an example of best practice in culturally appropriate health promotion. Borrowing from Aboriginal oral history traditions, dance and song, the play delivers specific health messages about HIV/AIDS and related matters. *No Prejudice* is strong, lively, dramatic theatre, with music, singing and lots of laughs. It is also powerful and moving.

4.6 EDUCATION IN PARTICULAR CONTEXTS

The prevention message can be reinforced in a number of non–health sector contexts: education institutions; prisons; among sex workers; among gay and homosexually active men; by people living with HIV/AIDS and their carers; and through cultural practices.

4.6.1 Educational institutions

Schools and other educational institutions are one of the most important non–health sector areas that can be used to improve and increase education on sexual health and related matters; for example, relationship building and child protection. Many Aboriginal and Torres Strait Islander communities, schools and other educational facilities are in a good position to provide information to students of all ages. This is especially the case in remote communities, where schools are key local institutions. Community priorities can be readily incorporated into school programs and, with support and guidance, local educational resources and projects can be developed by students. These programs can be placed in a holistic health framework or included in a variety of curricula, such as human development, Indigenous culture, science and sport.

Aboriginal health workers should be supported by the relevant State and Territory education departments in order to provide effective health education for children attending schools. In many cases, securing access to local schools has been difficult because of a failure to recognise the importance and value of having Indigenous health workers provide education and information for Aboriginal and Torres Strait Islander children within the school environment.



On Thursday Island, Torres Strait Islander health workers provide education and prevention awareness talks on STDs, contraception and general sexual health for school-aged children.

4.6.2 Prisons

The sexual health problems facing Aboriginal and Torres Strait Islander people in prison must be confronted. This matter is of particular concern because of the over-representation of Indigenous people in gaols. Culturally appropriate health care education should be provided for Aboriginal and Torres Strait Islander people in prison. Broader debate about access to condoms and clean needles for injecting drug users also needs to be encouraged: the ban on provision of such items may disproportionately affect Aboriginal and Torres Strait Islander people's health given their over-representation in the prison population. ANCARD will take a leading role in informing the States and Territories of best national and international practice, and encouraging their adoption.

Dealing with HIV/AIDS, and especially hepatitis C, in prisons is complex. Fundamental principles must be harm minimisation, the reduction of unsafe sexual and injecting drug behaviours, and a focus on peer education. Because the social and sexual behaviour of prison inmates may put their partners at risk, inmate's partners have specific education and prevention needs in the area of sexual health, including STDs, HIV and hepatitis C.

Recent moves in New South Wales to test the introduction of condom-vending machines to some correctional institutions suggest that harm-minimisation approaches can be effectively negotiated and implemented in environments that have previously rejected such approaches.

The Working Party supports the New South Wales initiative and will be closely monitoring its progress. It stresses, however, that risk behaviours do not cease at the time of release from prison and for this reason specific education for inmates, their families and partners should be considered a necessary adjunct to condom availability. In this way behaviour change and attitudinal change can be fostered not only in the correctional population but also in the wider community.

Redfern Aboriginal Medical Service provides regular doctor's clinics for Aboriginal and Torres Strait prisoners. The clinics deal with a range of aspects of health, including sexual health. Redfern also runs safe sex workshops for young people in youth detention centres. Eventually, this role will be shared by Aboriginal health services throughout New South Wales, which will provide similar services to prisons in their area.

It is vital that fundamental principles such as confidentiality in relation to HIV status are adhered to in the prison setting. Identifying individuals as HIV



positive can severely affect the willingness of people at risk to seek testing and the willingness of those with HIV to seek treatment. It also limits the effectiveness of education programs.

4.6.3 Sex workers

There is very little information available on Indigenous Australians' involvement in sex work, and this situation should be remedied. Further, in recognising diversity and difference in Indigenous communities, attention should be given to making existing peer education initiatives for sex workers more inclusive. Greater Indigenous access to such initiatives and to Indigenous educators is necessary. Sex worker programs should not be limited to people involved in commercial or organised prostitution: opportunistic sex work, particularly that associated with homelessness and youth, should be integral to prevention strategies.

4.6.4 Gay and homosexually active men

It is reasonable to assume that the range of sexual activity and identity in the general community is reflected in many Indigenous communities. There are Indigenous men who identify both with their Indigenous community and with gay and transgender communities. These men are at particular risk because they can become invisible in the prevention initiatives of both communities. It is possible to target these men through both the Indigenous and gay and transgender communities by incorporating images and messages about men who have sex with men in gay community prevention programs and in Indigenous community prevention initiatives.

The problem of Indigenous men who have sex with men but do not identify as gay is more complex. The experience gained by AIDS councils and State and Territory health authorities in targeting these men may be useful in Indigenous communities.

Although epidemiological data show that homosexual transmission accounts for 54 per cent of reported HIV transmission in Indigenous communities, the data do not reveal a complete picture of risk factors in relation to STDs, HIV and hepatitis C. It is important therefore that regional and local responses are developed using the best available local knowledge and evidence.

In some areas, AIDS councils are collaborating with Aboriginal primary health care services. Given the expertise of AIDS councils in prevention programs, particularly peer education for gay and homosexually active men, collaborative arrangements of this kind should be further developed around the country.

At the national level, the Working Party will encourage strong links with the National Gay Education Strategy and ensure that national sexual health programs and strategies are inclusive of Indigenous gay and homosexually active men.



4.6.5 People living with HIV/AIDS and their carers

Funding to enable people living with HIV/AIDS and those who care for them to play an integral part in education strategies should be made available as part of the overall education approach. Discrimination and isolation can be successfully dealt with only if meaningful, personal messages and experiences are conveyed. Much can be learnt from those already infected.

The development of local networks of trainers and educators should be facilitated; a register of trainers, speakers and support personnel should be developed for use in devising local or regional programs. Training should be accredited and regularly updated to meet the needs of individual communities. Train-the-trainer and skills-based training approaches will encourage competency, understanding and local commitment. In this way local priorities and cultural considerations can be sensitively and gradually accommodated with sufficient support.

4.6.6 Cultural practices

The transmission of blood-borne viruses through cultural practices has been identified as an area of concern even though there have been no documented cases of infection resulting from such practices.

To reduce the possibility of infection and the spread of transmissible diseases, a number of communities have developed strategies for encouraging safe cultural practices; among them are the use of clean equipment and the employment of ceremonial workers to reinforce the prevention message through STD and HIV education. Consultations and the availability of single-use equipment have meant that cultural activities can be continued.

A national approach to reducing the risk associated with cultural practices is inappropriate, but regional strategies should be developed to counter this potential threat for HIV transmission.

4.6.7 Resources and training

The strategies outlined need to be adequately resourced. Funds should be available for regional planning and coordination and for program evaluation. Specific training and long-term assistance should be provided through Aboriginal primary health care services, AIDS councils and health departments. This will ensure that education initiatives are based in a primary health care framework and are not isolated or marginalised as simply STD or HIV/AIDS 'talk'.

4.7 HARM MINIMISATION AND 'HEALTH HARDWARE'

The concept of harm minimisation has been a cornerstone of Australia's response to HIV/AIDS and has been credited as one of the main reasons for Australia's success in limiting transmission of the virus, particularly among injecting drug users.



The Working Party considers that a harm-minimisation strategy is central to preventing the spread of HIV/AIDS, hepatitis C and other related communicable diseases in the Indigenous setting. It emphasises, however, that harm minimisation as a concept does not come into conflict with strategies designed to create opportunities for a drug-free environment or lifestyle in Indigenous communities. The concept of harm minimisation needs to be reframed, to take into account the particular concerns of Aboriginal and Torres Strait Islander communities.

The term ‘harm minimisation’ is interpreted in widely varying and often conflicting ways, depending on the context in which particular professions, communities or behaviours are being discussed. In the context of this report, ‘harm minimisation’ is used to refer to a spectrum of strategies which may be used by individuals infected with and affected by HIV/AIDS, hepatitis C or other related communicable diseases, Indigenous health workers, health professionals and community groups. Basically, this approach provides a range of risk-reduction options for people at high risk of transmission of HIV/AIDS or other related communicable diseases without making moral, religious, political or personal judgments about the person or the behaviour in question.

This report attaches great importance to recognising diversity and difference within the Indigenous population, so this way of thinking about harm minimisation is particularly appropriate. Indigenous families and communities are not homogenous, and a variety of approaches must be available to educators and health professionals if they are to meet the needs of individuals, families and communities. Individuals require information and education in ways that reflect their personal learning styles, life experiences and priorities; families and communities need to be kept informed, so that they understand the reasons for education and prevention programs.

What is central to the diversity of approaches is the objective of reducing transmission of illness and disease and reducing the personal and social repercussions of those illnesses and diseases. Harm minimisation recognises that individuals will not always respond to moral or social pressures. Some individuals will continue to engage in risky or illegal behaviours, or both—often with consequences for other members of their family and community—and it is this wider community concern that is at the core of initiatives such as the provision of free and clean injecting equipment and condoms.

Of course, it is equally important to take into account the balance between an individual’s human rights and community well-being.

4.7.1 Needle exchanges

At present a number of needle-exchange services operate in Indigenous communities throughout the country. Some services have a high profile; others are discrete outreach programs operating away from main agency premises.



Some services developed an early response to injecting drug use in an attempt to limit the spread of blood-borne diseases. The Working Party's consultations confirmed that the maintenance and extension of needle exchanges is a priority.

Nu-hit needle exchange programs operate as drop-in centres and mobile outreach services. Each program focuses on confidentiality, the provision of free, clean injecting gear, education and prevention, reducing the social isolation of people using the service, collection of used equipment, and preventing the risk of 'needle stick' injury.

There is still much debate about the provision of needle exchanges in Aboriginal and Torres Strait Islander communities, and the Working Party considers that stimulating informed debate on this question is crucial to improving the sexual health of Indigenous people. Critical evaluation of the success of this approach in the mainstream health arena is necessary, and research into how well these approaches translate to Indigenous communities is essential. The provision of free needle-exchange mechanisms in the mainstream community appears to have been a vital element in preventing the spread of HIV and, more recently, in preventing the transmission of hepatitis C. A growing community concern about hepatitis C could lead to discrimination in much the same way as has occurred with HIV—and this should be guarded against.

For Indigenous communities that already have needle exchanges, further discussion about improving access to and the cultural appropriateness of the exchanges (especially hospital-based services) should be facilitated through the partnership mechanisms described in this report. For Indigenous communities without needle-exchange facilities, a great deal of community liaison and negotiation needs to occur before such services are introduced. This should involve community councils, representative bodies and other community groups in discussing needle exchanges as one option within a primary health care model.

The role of Aboriginal community-controlled health organisations and affiliated community organisations must be integral to this development approach, so that education can be linked with other preventive measures. Community fears—about used needles and the lack of 'sharps' bins, for example—must be allayed and a framework for counteracting these fears should be developed. The Commonwealth must ensure that resources are directed in such a way as to take account of these concerns, as should the review of the Aboriginal and Torres Strait Islander Substance Misuse Program and the National Drug Strategy.

The mobile needle and syringe exchange program is a project of the health promotion unit at the Perth Aboriginal Medical Service. Particular attention is given to harm minimisation through continuing education and information sharing in a confidential, non-threatening environment.



4.7.2 Condoms

The Working Party's consultations confirmed the need to maintain and increase access to condoms as part of education programs and primary health care. Condoms should be freely available. Access to them is crucial to the success of education programs: they can be used for demonstration purposes and to encourage behaviour that will help prevent the spread of STDs and HIV/AIDS. A number of community surveys of the viability of condom-vending machines and other outlets in communities have shown the need for multiple access points and maintenance of reasonable prices.

The mainstream response to HIV has focussed on a culture of safe sex. The sensitivities of condom promotion in an Indigenous context must be acknowledged, and strategies to increase condom use and to overcome economic and cultural barriers must be developed.

4.8 CREATING A DISCRIMINATION-FREE ENVIRONMENT FOR PREVENTION

Much work remains to be done—both in the mainstream community and in Aboriginal and Torres Strait Islander communities—to ensure that people are not discouraged from seeking diagnosis and treatment of STDs, HIV/AIDS, hepatitis C and other blood-borne diseases.

The media have a primary role to play in creating an environment free of discrimination. They should not draw unwanted attention to communities that are struggling with high rates of STDs and HIV/AIDS, nor should they reinforce community misconceptions about the causes of sexual ill-health among Indigenous Australians. The media must be committed to reporting on sexual health in keeping with the protocols developed by the Working Party (see Appendix C).

The notion that HIV/AIDS is somebody else's problem is misleading and dangerous. HIV/AIDS does not discriminate: it attacks men and women, young and old, Indigenous and non-Indigenous. Increasing people's awareness of how the virus operates helps individuals and communities to show their concern and to care for people affected by the disease. This then enables communities to share responsibility for reducing the overall impact of the disease.

The Working Party notes that some barriers still discourage Aboriginal and Torres Strait Islander people from seeking diagnosis and treatment of STDs, HIV/AIDS, hepatitis C and other blood-borne diseases from mainstream services. Whether these barriers are real or perceived is largely irrelevant. The crucial factor—highlighted during the consultations—is that Aboriginal and Torres Strait Islander people feel that some mainstream services do not welcome them. This is of particular concern in relation to the continuing management of HIV/AIDS because the best knowledge of treatment options



resides within mainstream bodies such as AIDS councils and hospital AIDS units. Service barriers must be identified and access to mainstream services must be improved.

The Working Party also notes that there is still considerable concern among Indigenous gay men and injecting drug users that they will not be dealt with in a non-discriminatory manner by Aboriginal health services. Again, whether this is the case or not is largely irrelevant—the perception greatly reduces the likelihood of these people seeking appropriate care. The Working Party stresses, however, that it is vital, in confronting these difficulties, to acknowledge and build on the strength of existing family and community relationships.

Reducing discrimination is a complex task, and the participation of Aboriginal primary health care services is critical if the spread of STDs is to be reduced and HIV is to be controlled. Some Aboriginal health services have begun tackling the problem of denial and lack of access by commissioning confidential studies of members of identifiable groups or consumers; for example, gay men's access to medical treatment.

To help health services meet the needs of those most affected, strategies such as the following may prove useful:

- adopting service policies that do not discriminate against gay men and lesbians;
- pursuing rigorous policies on the confidentiality of client information;
- taking a harm-minimisation approach to injecting drug users;
- ensuring that groups at risk of discrimination are represented on health service boards.

4.9 THE LEGISLATIVE FRAMEWORK

The third National HIV/AIDS Strategy insists that a supportive legislative environment is integral to Australia's success in responding to HIV. In relation to law reform the objective of the third Strategy is

that the Commonwealth and the States and Territories should regularly assess policies and legislation to ensure that impediments to the prevention of HIV/AIDS and related communicable diseases continue to be reviewed and removed and that discrimination connected with HIV/AIDS and related communicable diseases is effectively combatted (Department of Health and Family Services 1996, p. 67).

The third Strategy notes that the Aboriginal and Torres Strait Islander Commission is the principal Commonwealth agency responsible for coordinating the Government's response to the Royal Commission into Aboriginal Deaths in Custody and that legal and custodial matters affecting



Indigenous Australians will be considered within this context. It also offers six guiding principles to complement and assist education and other public health measures.

- Principles of access, equity, participation and equality for individuals, a client focus, and a supportive legislative environment, are integral to Australia's success in responding to HIV/AIDS and related communicable diseases, notably hepatitis C.
- People living with HIV/AIDS, and those with other serious chronic diseases such as hepatitis C, have the same rights to accessible, quality and confidential legal information and advice as other members of the community, without fear of discrimination.
- Law reform should take a rational, human and responsive approach to the significant issues that are presented by HIV/AIDS and related communicable diseases.
- Laws specifically created to deal with HIV/AIDS alone require particular justification.
- Reform measures should be as uniform as possible across jurisdictions.
- Policies designed to eliminate continuing patterns of discrimination and to reduce prejudice and violence directed against homosexual or transgender people, people with HIV/AIDS or hepatitis C and injecting drug users should be promoted by all governments. (pp. 67, 68)

Given the particularly harsh impact of the judicial system on Aboriginal and Torres Strait Islander people, it is of even greater importance that these principles are adhered to. Governments must recognise the crucial role of the law in contributing to an environment that maximises our ability to respond effectively to HIV/AIDS and other related communicable diseases.

In terms of the legislative environment, the Working Party's task will be to monitor those areas where there may be impediments to prevention and care efforts and to provide advice to ANCARD to make sure the legislative framework takes account of such impediments. It should be noted that, as part of the National Public Health Partnership process, the Commonwealth and State and Territory governments will be examining public health legislation reform.

Protection of confidentiality was identified as a major concern during the Working Party's consultations. Confidentiality is vital if there is to be a supportive environment for HIV prevention efforts and if people are to be encouraged to seek treatment and care. This poses challenges where clients and health care workers may have personal or family links.

The Working Party recommends that the States and Territories review current legislation and guidelines to ensure that legislative protection exists and is well understood. At the service level, organisations should ensure that



confidentiality protocols and processes exist and are regularly monitored and reviewed.

One area of interest to the Working Party is the way in which jurisdictions deal with individuals whose behaviour exposes others to the risk of HIV infection. Overly coercive and restrictive responses to recalcitrant behaviour, particularly where the individuals involved are members of already marginalised groups, may force such behaviour 'underground' and may even alienate people who are behaving responsibly.

In most circumstances behaviour that places others at risk of infection can be modified through effective education and counselling. At the same time, however, we must recognise that there will be extraordinary circumstances, when recalcitrant behaviour is best dealt with through coercive measures. Questions surrounding the appropriate grading and application of coercive measures, and processes for their review and appeal, are discussed in some detail in the final report of the Intergovernmental Committee on AIDS Legal Working Party and in the discussion paper that preceded that report. The final report made the following recommendation:

Powers in public health legislation to place restrictions on the living circumstances and employment of HIV-infected persons who put others at unreasonable risk of infection should be characterised by a graded series of interventions and only used in exceptional cases, with isolation being a last resort. (Legal Working Party 1992, Recommendation 2.5.1)

Although public health legislation does reflect this recommendation there is anecdotal evidence that in some jurisdictions responses can be overly coercive when dealing with Indigenous people. Of particular concern is the potential for indiscriminate or inappropriate use of legislation that may be counterproductive to education and prevention efforts. More specifically, there is concern about the potential for discrimination against Indigenous people. These are matters that the Working Party will need to monitor and, if necessary, provide advice to ANCARD on further action.

Success in limiting the transmission of STDs and HIV/AIDS is dependent on a non-judgmental environment in which people feel free to discuss risk behaviours. It is also necessary to make a clear distinction between risk behaviours and people living with HIV/AIDS. People living with HIV/AIDS are not the big threat: risk behaviours are.

A supportive legislative framework is essential. It must embrace the principles of public health, which need to be complemented by initiatives that support the rights of people to enjoy sexual and reproductive behaviour, enable access to the necessary services, and reduce the risk of unnecessary exposure of oneself and others to harmful diseases.



The legislative framework must acknowledge that Traditional Law is still practised in many Indigenous communities. Without this acknowledgment, it will be difficult to involve communities in developing realistic and appropriate responses to behaviours associated with sexual health.

The Working Party will also give consideration to legislative issues connected with data collection (see Section 7.8 for further discussion on data collection).





Treatment, care and support

5.1 INTRODUCTION

Under the third National HIV/AIDS Strategy, the objective of the Treatment and Care Program is to ‘identify and provide access to systems of care and support that will promote health and maintain quality of life for people living with HIV/AIDS’ (Department of Health and Family Services 1996b, p. 48). This chapter deals specifically with the needs of people living with HIV/AIDS. Treatment and care associated with STDs are discussed in Chapter 4.

Treatment, care and support are seen to encompass a range of concerns, including testing for HIV, early access to health maintenance programs, management of HIV-associated conditions, and counselling and support for people living with HIV/AIDS, their partners, families and carers.

During the Working Party’s consultations it became very clear that the current treatment and care needs of Aboriginal and Torres Strait Islander people living with HIV/AIDS and of their partners, families and carers are not being met. Indigenous Australians with HIV/AIDS are not being diagnosed early, are not receiving high-quality information about treatment options, and are not being included in clinical trials of new treatments. It is also evident that the care needs of Indigenous Australian’s with HIV/AIDS either are not being met or are being provided by already over-stretched family and community networks, which in turn are not sufficiently supported. The lack of culturally appropriate support services for Aboriginal and Torres Strait Islander people living with HIV/AIDS has a significant and negative impact.

People living with HIV/AIDS are central to the development, defining and planning of education and prevention and treatment and support strategies, including a continuum of care. Their input into program planning is a key component of developing effective strategies. It is also important to recognise that these people still face discrimination and stigmatisation and they need to be supported and empowered.

A number of factors should be taken into account in devising strategies for the treatment, care and support of Aboriginal and Torres Strait Islander people living with HIV/AIDS:

- Close family ties and the strength of social organisation within Aboriginal and Torres Strait Islander communities lead to families and communities taking a high level of responsibility in caring for the sick.

- This caring often takes place in an environment where there are significant social and economic burdens, such as racism, poverty, unemployment and poor living conditions. Caring for people with HIV/AIDS in such an environment often places additional stress on people already dealing with substantial pressures.
- Aboriginal and Torres Strait Islander people living with HIV/AIDS will often move from one community to another—from the city back to a rural community to be with family, for example, or from a remote area to the city to seek better care.
- A relatively small number of Aboriginal and Torres Strait Islander people are infected with HIV/AIDS, making mass approaches to treatment and care unworkable.
- Discrimination against Indigenous people with HIV, particularly gay men, affects the provision of treatment and care, both within Aboriginal and Torres Strait Islander communities and in the mainstream.
- Flexible treatment and care approaches are needed that take account of the considerable diversity of circumstances of those infected, including their wide geographic spread.
- Individual, partnership, family and community needs must be approached within a framework that recognises the significance of men's and women's business.
- The treatment choices of people with HIV/AIDS should be supported.

The important question of 'shame' and how it operates within Aboriginal and Torres Strait Islander communities also affects the delivery of treatment and care. Having HIV can make an Indigenous person feel shame and can also make their family feel shame. This may lead to a person with HIV being, or feeling, alienated from their family, which places another great burden on them.

Fear of HIV/AIDS and homophobic attitudes still reside in Aboriginal and Torres Strait Islander communities, as they do in the mainstream community. There is a need to ensure that a person with HIV/AIDS has complete control over who knows about their HIV status that there are positive approaches to reducing the stigma and discrimination faced by people living with HIV/AIDS. This must be done so that all those who need treatment, care and support feel able to openly seek it.

5.2 TREATMENT

Three elements are essential to the diagnosis and management of HIV for Aboriginal and Torres Strait Islander people:

- improving access to advances in HIV treatment;



- improving the capacity of primary health care services to deliver high-quality treatment and care to Aboriginal and Torres Strait Islander people living with HIV/AIDS;
- strengthening partnerships between Indigenous and mainstream agencies.

People living with HIV/AIDS and their families and carers have an essential role in developing policies and strategies for service delivery.

In some areas a broad range of agencies and services provide for the treatment and care needs of people with HIV. Many Indigenous people with HIV/AIDS will choose AIDS councils, urban general practitioners and hospital and community services for their care: these services must adapt to the needs of Indigenous people with HIV/AIDS and their carers. This should occur within a local-level framework in collaboration with Aboriginal health services.

5.2.1 Improving access to advances in HIV treatment

As outlined in the third National HIV/AIDS Strategy, there were significant advances in treatment and care during the period of the second Strategy. In particular, during the last year of that Strategy there were rapid developments in knowledge about HIV replication throughout the course of infection, about the nature of the immune response required to combat HIV, and about the impact of combination antiretroviral therapy and monitoring viral load to guide management of the infection. In the light of these advances, standards of care for therapy, including monitoring of treatments, will probably change rapidly in the next few years. The advances in treatment will enable people living with HIV to live well for longer and in general improve their quality of life.

It is critical to ensure that Aboriginal and Torres Strait Islander people living with HIV/AIDS are in a position to receive the full benefit of recent advances in treatment and care. The third National Strategy's emphasis on a continuum of care is of even greater importance in the context of Aboriginal and Torres Strait Islander communities. The Feachem report called particular attention to the need for services used by people with HIV/AIDS to prepare for an increase in the number of Aboriginal and Torres Strait Islander people using the services.

Advances in understanding of HIV, and its treatment, are also greatly increasing the complexity of HIV management. It is essential that Aboriginal and Torres Strait Islander people living with HIV/AIDS receive up-to-date information about changes in standards of care for HIV/AIDS, so that they can make informed choices about treatment regimes. Action should be taken to ensure that, as knowledge about HIV disease progression increases and the range of treatment options extends, Aboriginal and Torres Strait Islander people can participate in health maintenance education to encourage uptake of and compliance with new treatments.



Clinical trials

Clinical trials aim to establish the efficacy and safety of a drug or treatment and to identify groups of patients who can be expected to benefit from the drug or treatment. Aboriginal and Torres Strait Islander people have not had the opportunity to participate in clinical trials to date.

The Clinical Trials and Treatments Advisory Committee, a subcommittee of ANCARD, has responsibility for providing advice on best practice in HIV/AIDS treatment and management, including advising and approving clinical trials of new HIV/AIDS treatments. The Committee should develop strategies to ensure that Aboriginal and Torres Strait Islander people have equitable access to trials and the latest treatments.

5.2.2 Improving the capacity of primary health care services

Early intervention

The role and importance of early intervention in HIV/AIDS management should become a subject for community debate. At present, successful treatment depends on early intervention, as soon as possible after infection. Early intervention offers benefits for both the individual and the community at large. Anecdotal evidence suggests that HIV is not being diagnosed early among Aboriginal and Torres Strait Islander people: strategies must be developed to encourage people at risk to come forward for testing. The Commonwealth should facilitate widespread debate about early intervention.

Pre-test information and post-test counselling¹

Pre-test information is crucial for ensuring that a person being tested for HIV gives informed consent. At the very least, informed consent means a person understands the medical implications of HIV infection and is fully aware of the psychological, social and legal implications of their condition. It also provides an opportunity to give the person preventive information, such as information about safe sex and safe injecting drug use.

In the context of Aboriginal and Torres Strait Islander communities, successful delivery of pre-test information depends on factors such as language barriers (particularly when the person being tested speaks a language other than English) and other communication differences between non-Indigenous and Indigenous people.

Sensitivity is essential when informing an Aboriginal or Torres Strait Islander person of their rights and responsibilities in relation to testing for STDs and HIV. Some Indigenous people prefer to see a non-Aboriginal health worker for pre-test information and post-test counselling for a variety of reasons. In some situations avoidance relationships exist between particular health workers and

¹ The terminology for pre- and post- test counselling has changed, it is now 'pre-test information and post-test counselling'

A decorative graphic at the bottom of the page, consisting of a horizontal band with a repeating geometric pattern of small squares and diamonds, transitioning from a light yellow to a darker gold color.

community members and these affect the service options available to those community members.

The importance of appropriate and effective pre-test information and post-test counselling is highlighted in the case of antenatal testing. Concerns about things such as access to antiretroviral treatments during pregnancy, support mechanisms for children and parents, and the availability and accessibility of treatment and care need to be accommodated.

It is also important to ensure that information is provided in a manner a person can understand; this may include the provision of video cassettes that can be taken home or audio tapes that can be listened to in private.

The following are suggested strategies for the good management of pre-test information and post-test counselling:

- developing policies with organisations and regions that outline the best way to approach pre-test information and post-test counselling;
- providing information to individuals in a format they can use and understand;
- allowing individuals sufficient time to make their decision;
- ensuring complete discretion and confidentiality;
- providing details of where the individual can go for more information, which may include specialist agencies or a recognised support person in the community.

The Commonwealth should take a lead role in facilitating the development of appropriate guidelines for pre-test information and post-test counselling for Aboriginal and Torres Strait Islander people.

Confidentiality and privacy

If Aboriginal and Torres Strait Islander people are to be willing to attend health services for testing and treatment they need to be confident that effective confidentiality and privacy mechanisms exist within their health services. These mechanisms should be developed by Aboriginal health services. The Commonwealth could assist by facilitating discussion of this question and by helping primary health care services to develop local confidentiality and privacy strategies.

Anyinginyi Congress Aboriginal Medical Service in the Northern Territory realised that people would not use the service unless they were totally sure that information about them would be confidential. To change this, Anyinginyi instituted structures, bought the necessary equipment, and developed standardised procedures for recall, follow-up and treatment for pap smears, STDs and HIV. Particular attention was paid to the development of protocols for positive HIV results.



Tuberculosis–HIV co-infection

Tuberculosis–HIV co-infection remains low in Australia, but the potential for an increase in HIV-related tuberculosis was noted in the Feachem report. Some Aboriginal and Torres Strait Islander people are at high risk of tuberculosis infection, so this situation should be closely monitored. Tuberculosis occurring with HIV is manageable provided it is recognised early and managed in accordance with standard guidelines.

The National Health and Medical Research Council Tuberculosis Working Party is developing a draft Strategy, ‘Towards Elimination of Tuberculosis 11: guidelines and protocols for controlling tuberculosis in Australia’. The draft identifies Aboriginal and Torres Strait Islander people as a priority group for action. It puts forward strategies to promote community awareness, education of Indigenous health care workers, and tuberculosis treatment regimens that satisfy the specific needs of Aboriginal and Torres Strait Islander communities, and emphasises directly supervised and observed therapy and compliance, contact tracing, screening, immunisation and use of preventive therapy. The strategy will be released soon.

Hepatitis C–HIV co-infection

Hepatitis C may occasionally co-exist with HIV. In Australia, however, hepatitis C is largely associated with populations who are not infected with HIV. Principles for the treatment and care of people with hepatitis C are incorporated within the National Hepatitis C Action Plan (see Section 3.2.4). There are also concerns around the treatment, care and clinical management of people who are HIV positive and also use recreational and other drugs. For example, those who may have had a long exposure to opioids (such as heroin) and other psycho-active agents may have considerable tolerance to many pain-relieving medicines. There is also a likelihood of co-infection with hepatitis B and C, and this must be taken into account when selecting therapy and monitoring progress.

Resourcing

The third National HIV/AIDS Strategy notes the desirability of moving the management of HIV treatments into the primary health care sector. If this is to work successfully in the Aboriginal and Torres Strait Islander context, the primary health care sector will need to be adequately resourced in terms of staffing and information to enable staff to provide high-quality treatment and care.

Information systems

To remain effective in providing high-quality treatment and care, services must have suitable information systems. National mechanisms must be developed to ensure that local-level services receive up-to-date information on treatment, which should be provided in a format that can meet the diverse needs of



Aboriginal health workers, nurses, doctors and service managers. In this way services will be able to update their clinical care guidelines for HIV/AIDS treatment as necessary. Some ways of distributing this information are regular newsletters, seminars, summaries of journal articles, sites on the Internet, and training using video links.

Strengthening partnerships

An important part of maintaining high-quality treatment and care is the strengthening of partnerships. In the context of this report, this means the development of agreements between Indigenous and mainstream agencies. Aboriginal community-controlled primary health care organisations should begin to liaise closely with agencies that have the best information on treatment and care options. Among these agencies are AFAO and its affiliates, the National Association for People Living with HIV/AIDS, specialist sexual health services, and the three research centres concentrating on HIV².

Links should also be developed between services and specialist groups that have particular expertise in HIV/AIDS treatment and care. Among these groups are the Royal Australian College of General Practitioners, the Australasian College of Sexual Health Physicians, and the Australasian Society for HIV Medicine.

The Working Party's consultations confirmed the importance of close links between Aboriginal community-controlled health services and AIDS councils. Many of the AIDS councils report that they are providing prevention and care services for Indigenous people: counselling, home care treatment information, and youth self-esteem and other services have been used. Among specific initiatives are the establishment of an Indigenous gay men's education project in one State, inclusion of Indigenous images in gay education campaigns in two States, and the provision of male and female Indigenous health workers in another State.

There are also numerous examples of collaboration between AFAO affiliates and Indigenous services in the States and Territories. Examples are collaboration between the Northern Territory AIDS Council and Danila Dilba in Darwin, use of Victorian AIDS Council counselling facilities by staff from the Victorian Aboriginal Health Service, and participation by the New South Wales Users and AIDS Association in a Koori injecting drug users peer education project in Redfern.

Another initiative is the AFAO Indigenous Gay and Transgender Working Group, established following the 'Awernekenhe' Conference. The Group is made up of Indigenous gay and transgender representatives from each State and Territory and has met regularly in the last two years to oversee

2 The National Centre in HIV Epidemiology and Clinical Research, the National Centre in HIV Social Research and the National Centre in HIV Virology Research.



implementation of the Conference's recommendations. The Group provides the AFAO executive with advice on matters relating to Indigenous gay and transgender people and oversees the Commonwealth-funded project that was established late in 1996 to work on implementation of the Conference's recommendations.

These recent developments in local collaboration provide an example for working together to improve services to Indigenous people living with HIV/AIDS, their carers and their families. Arrangements between AIDS councils and Aboriginal health services, such as those developed in the Northern Territory, have the potential to offer people living with HIV/AIDS access to a wider choice of services and health professionals as well as ensuring that available services are expanded to meet specific needs rather than to duplicate other services. At a local level this process could be facilitated (possibly through pilot programs) by closer collaboration between the relevant peak bodies, such as NACCHO and AFAO. Research and evaluation should accompany any such initiatives, and the development of best-practice models and training resources should be a priority.

Treatment, care and support in rural and remote areas

The Working Party found that there were particular concerns about treatment, care and support in rural and remote areas. The impact on small communities of caring for people with HIV/AIDS was stressed in consultations. This impact is often magnified by the already high level of ill-health and the under-resourcing of agencies responsible for delivering health care. The consultations confirmed that many people who live in rural and remote areas feel they are unable to gain access to the range of services available to people in metropolitan and urban areas. The Working Party stresses the importance of developing strategies to make services more accessible for people living with HIV/AIDS in rural and remote areas.

The third National HIV/AIDS Strategy notes that service delivery for people living with HIV/AIDS will be improved if the States and Territories develop and publish action plans for HIV treatment and care in their communities. It is important that these action plans articulate strategies to meet the needs of Aboriginal and Torres Strait Islander people with HIV/AIDS. Different modes of service delivery (from in-patient treatment to intermediate care to community-based care) and different types of service (such as mental and dental health services) must be taken into account.

5.3 SUPPORT SERVICES

Its consultations led the Working Party to conclude that existing support services for Indigenous Australians living with HIV/AIDS are not sufficiently coordinated, are generally under-resourced, and are often not tailored to the specific needs of Aboriginal and Torres Strait Islander people. There was a



strong view that if support initiatives are to be effective they must respond to the diversity in Aboriginal and Torres Strait Islander communities. Many submissions stressed the need for support and training mechanisms that are relevant to the needs of local communities. It was also widely held that ‘blanket’ approaches to support services would probably be unsuccessful.

Aboriginal and Torres Strait Islander people face different problems in terms of access to support, depending on where they live. In urban areas, where mainstream services are well developed, Indigenous peoples’ particular needs do not appear to be taken into account. In rural and remote areas, where the number of people with HIV/AIDS is small, few mainstream services deliver support related to HIV/AIDS. Aboriginal and Torres Strait Islander people in general have great difficulty in gaining access to broader care and support services, such as disability services, in rural and remote areas and where the services are available they are not equipped to deal with the support needs of HIV positive people.

It is also important to remember that in some cases discrimination has forced individuals to leave their home areas and move to urban centres. This leads to cultural and social isolation, which can have serious implications for the delivery of counselling and support services and effective education messages.

Further to this, many individuals—whether through discrimination, uncertainty or dislocation—have lost or do not maintain contact with their families or home communities. The need for people to have a range of support services to choose from is fundamental.

The movement of people away from family and country also poses serious problems in terms of continuity of care and access to services and support. Although the number of HIV-positive Indigenous people progressing to serious illness is small and predominantly clustered in some of the major cities, many of these people do travel home to be with family or to die.

It is at this critical time that resources are at their most scarce. Treatment and medication avenues may be extremely limited, if available at all, and family support networks may well be limited by discrimination and fear. Current funding structures are not conducive to the provision of services to a mobile client, particularly in a community where only a few individuals are HIV positive.

The Working Party’s consultations also confirmed that the support needs of Aboriginal and Torres Strait Islander people are often hampered by economic factors such as a lack of money for food or medicine and not having access to transport.

5.3.1 A coordinated approach

The Working Party is conscious of the consultations’ emphasis on lack of coordination in the provision of support services. One model that may be useful in meeting the treatment, care and support needs of Aboriginal and



Torres Strait Islander people living with HIV/AIDS is the case management, or ‘brokerage’, approach. The Working Party considers, however, that community liaison with health services should be encouraged if suitable models are to be developed for specific communities’ circumstances.

A case management approach would entail a case manager taking responsibility for ensuring that the support needs of a person living with HIV/AIDS were met. The case manager could be someone working within an Aboriginal health service, a disability service provider, or someone in a broader Aboriginal community organisation, or an organisation providing medical services. The case manager would be responsible for a ‘seamless’ approach to support—that is, that all needs were met—and would substantially reduce the need for the person living with HIV/AIDS or their carers, or both, to deal with a number of different service providers.

Although the case managers would draw on existing resources, it may also be necessary to provide additional funding so that they can buy specific services. Under this approach, resources would be seen to ‘follow the individual’. This may be particularly relevant in rural and remote areas, where services are already under-resourced and might not be able to absorb the additional costs of providing services to people living with HIV/AIDS.

This ‘brokerage’ model could allow individuals and their families (including families of choice) some degree of direct control over service delivery, through the case manager. It would also encourage the development of a client focus within service delivery organisations. A number of training, management and accountability issues are associated with this type of approach, but these could be dealt with through the development of appropriate structures and through adequate resourcing of organisations to carry out the case management role.

A case manager can use a range of services, which would differ substantially between urban and rural and remote areas. It is vital to strengthen all support services’ capacity to accommodate the particular needs of Aboriginal and Torres Strait Islander people living with HIV/AIDS, whether or not a case management approach is adopted.

5.3.2 Collaboration

The Working Party’s consultations revealed the need for improvements in liaison and coordination between all those involved in policy development and program implementation for care and support, especially between government and community-based sectors and between Indigenous and mainstream services. Effective HIV/AIDS support requires a big improvement in service collaboration and coordination.

Under the third National HIV/AIDS Strategy, State and Territory health authorities are responsible for the development and publication of HIV/AIDS treatment and care action plans. Under the Aboriginal health framework



agreements the joint planning forums are responsible for developing regional planning approaches to Aboriginal health services and environmental health.

At the national level, it will be the Commonwealth's responsibility to facilitate the development of best practice and its incorporation within existing planning mechanisms. In addition, the Commonwealth will need to encourage collaborative partnerships in the delivery of care in order to achieve continuity of high-quality care between the relevant health care providers. The Commonwealth will also have a role in developing links between the State and Territory HIV/AIDS treatment and care action plans and regional planning processes. One purpose of such planning mechanisms will be to improve the links between primary health care services and specialised HIV/AIDS-related services and between the primary health care and public health sectors.

Redfern Aboriginal Medical Service has developed a series of videos with accompanying booklets on sexual health. The video *Spread the Word: dealing with and caring for a person with AIDS* has been recognised internationally by being chosen for inclusion in the World Health Organisation kit; it is also used by the Deafness Council because of its accessibility to people with hearing difficulties.

5.3.3 Rural and remote areas

Innovative models for accommodating the support needs of people living with HIV/AIDS in rural and remote areas are urgently needed. Aboriginal and Torres Strait Islander people with HIV/AIDS in remote and rural areas have the same rights to treatment, care and support as people living in urban settings.

One model put forward during the consultations would see integration of the care of people with HIV/AIDS into the broader care and support networks of the community. It was acknowledged that, while the clinical aspects of HIV required specific treatment, many of the support needs were common across a range of chronic diseases and disabilities. By enhancing the ability of local agencies to meet the needs of chronically ill people in general, those agencies and their community support networks would be better equipped to meet the needs of HIV-positive people. The care and support needs of HIV-positive people would be managed in the same way as the needs of any other people with chronic illness are managed. This type of approach could have the desirable spin-off of educating the community about HIV, thus tackling the problem of discrimination.

The Working Party recommends that this coordinated approach to meeting the needs of Aboriginal and Torres Strait Islander people living with HIV/AIDS in rural and remote areas be piloted and evaluated. It is also necessary to review current funding of support agencies, particularly in those rural and remote areas where HIV-positive people are living, to ensure that they are adequately



resourced. In reviewing funding, it is important to be mindful that some of the demand on rural and remote services from people living with HIV/AIDS will be intermittent, when people visit their families.

5.3.4 Housing

The housing needs of Indigenous people living with HIV/AIDS warrant attention. Housing agencies, both Commonwealth and State and Territory, should work cooperatively to ensure that these people's housing needs are identified and accommodated. The availability of appropriate housing will become increasingly important for Indigenous people with HIV/AIDS in rural and remote areas.

The Working Party recommends that the Commonwealth facilitate discussions between relevant organisations—including Aboriginal Hostels Ltd and the community housing sector—with a view to addressing this situation. At the State and Territory level, collaboration between services, particularly those dealing with HIV-positive Indigenous people and the AIDS councils, would be useful to identify housing options and ways of securing the accommodation that is available.

5.3.5 Aboriginal health workers

Attention must be paid to the problem of 'burn-out' among Aboriginal health workers. These people should be able to discuss their work with a professional supervisor, in confidence, and they must have access to up-to-date training and be able to attend seminars on new treatments and methods of care and support.

5.3.6 Support for Aboriginal health services

The Office for Aboriginal and Torres Strait Islander Health Services in consultation with the Indigenous Australians' Sexual Health Working Party is developing a resource kit for primary health care services on addressing care and support issues for people infected with HIV. The kit aims to help Aboriginal and Torres Strait Islander and mainstream primary health care services to deliver 'user-friendly' services that respect the rights of individuals to quality care and support. A reference group of people personally and professionally affected by HIV/AIDS is assisting with the development of the resource kit.

5.3.7 Affiliated care organisations

There is an obvious need for home care services and other accommodation services to employ and train more Indigenous staff and provide more appropriate service options. Such training will require a point of delivery and this should link with the national accreditation approach noted in Section 5.3.6.



5.3.8 Respite care

Caring for someone who requires a great deal of support places considerable stress on the carers and family members. People living with HIV/AIDS have the same respite care needs as people living with other chronic conditions. Improving respite care services more generally may result in improved services for people living with HIV/AIDS.

The Working Party stresses the need for adequate respite care services, employing Indigenous workers, to be made available to Indigenous people with HIV/AIDS. Apart from reducing the stress for carers, this will help people to stay in their communities.

The potential for non-professional, community-based support arrangements, as have been seen in the mainstream, was referred to in a number of the Working Party's consultations and the submissions it received. Volunteer support was seen as crucial for people living with HIV/AIDS and their families, and especially important for people caring for their infected partners.

5.3.9. Conclusion

There are currently very low reported numbers of Aboriginal and Torres Strait Islander people living with HIV/AIDS. The Working Party considers that now is the time to develop effective strategies to ensure that these people have access to appropriate treatment, care and support.



The health workforce

As is stressed throughout this document, the primary health care sector has a very important role in reducing the rate of STDs and thus helping to prevent the transmission of HIV in Indigenous communities. Aboriginal and Torres Strait Islander health workers are integral to the work of the primary health care sector.

The success of implementing this report will depend on Indigenous field workers with clinical and educative experience who are prepared to travel to, train, support and resource communities on a regular basis, and on cooperation between Aboriginal health services, communities and field workers, mainstream health service providers, and all levels of government.

Aboriginal and Torres Strait Islander health workers have been employed in Indigenous communities for many years, providing a range of health care services. The significance of Indigenous health workers lies not just in their delivery of primary health care but also in their being from and of the community, sharing its aspirations and burdens. They are in a position to take what is useful from medical science, blend it with community understandings, and achieve better health outcomes.

It is difficult to define the role of a health worker, but among their many functions are:

- traditional health
- cultural brokerage
- clinical care and Western medicine
- health promotion
- environmental health
- community care
- administration, management and control
- policy development and program planning.

Overseeing the development of workforce strategies and policies is one of the responsibilities of the Aboriginal and Torres Strait Islander Health Council. The Office for Aboriginal and Torres Strait Islander Health Services has a responsibility for implementing workforce programs, including those arising from this report.

6.1 RESOURCING

The Working Party's consultations confirmed an urgent need for an increase in the number of Indigenous health workers, especially men given the under-representation of men, and because of the gender specific nature of men's and women's business. More positions for Indigenous health workers and more training places for Indigenous people who want to become health workers are necessary. This need was also stressed in the evaluation of the National Aboriginal Health Strategy (National Aboriginal Health Strategy Committee 1994) and the report of the Sexual Health Forum in Alice Springs (ANCA 1995). Having a pool of trained, multi-talented Aboriginal and Torres Strait Islander health workers will also greatly increase the capacity for developing innovative approaches to sexual health. These initiatives must be properly resourced.

6.1.1 Health worker training

Given the extensive responsibilities of, and duties performed by, Aboriginal and Torres Strait Islander health workers, training and continuing professional development are essential to maintaining workers' skills. Such training must be developed through existing partnership agreements (such as the health framework agreements) and major training institutions (both Indigenous and non-Indigenous) throughout the country. The Commonwealth should provide leadership in facilitating agreements on student intakes and career path development.

Regional-level specialist workers may be useful in providing support and training for generalist health workers. Generalist health workers have a vital contribution to make to prevention activities, but they require support in the development of more specific skills. Training programs need to account for individual skills, preferences and abilities—they should not assume that each Aboriginal or Torres Strait Islander health worker is willing or able to successfully carry out the diverse and specialised roles demanded of them.

Basic Indigenous health worker training should include training in sexual health and related fields such as counselling, communication and health promotion. Sexual health studies should overlap with areas such as clinical care, program development, community care, child protection, management of teams, administration and research.

All such sexual health training must be accredited, so that workers are able to develop skills that can be applied in a range of arenas. Accreditation should be linked with the development of workforce standards and training competencies and should be managed through to a local level in individual institutions.

Where appropriate, gender-specific training should be incorporated. It would provide scope for workers to localise training skills and perform education functions within the community.



Links between Aboriginal health workers should be enhanced through professional associations (particularly health worker representative bodies), workforce initiatives and regional coordination. Informal networks should also be fostered through local forums, tele-conferencing, video-conferencing, and regular inter-agency meetings that involve workers, management and community members. The provision of emotional and professional support should be integral to this, as should the use of mechanisms to disseminate information and discuss issues with stakeholders in the community.

6.1.2 Doctors, nurses and allied health workers

Other health professionals who work in Aboriginal community-controlled health services also require training if they are to play an effective role in management of sexual health. This training needs to be developed in conjunction with the relevant professional and representative bodies—the Royal Australian College of General Practitioners, the Australasian College of Sexual Health Physicians, the Australasian Society for HIV Medicine and the Australian Nursing Federation, for example—and in collaboration with Indigenous health bodies and training institutions. Coordination is necessary, so that all health professionals are able to work cohesively in developing and implementing innovative approaches to local and regional sexual health.

Within the primary health care sector, training and education for board members and management are also vital. These people are very influential in policy development and implementation in their organisations.

6.1.3 Retention of Aboriginal health workers

The high attrition rate for Aboriginal and Torres Strait Islander health workers may be attributed to a lack of support and the demanding nature of their work. These people need the opportunity to debrief and receive professional support and supervision in the workplace. Additionally, an important factor in job satisfaction is recognition of the important role Indigenous health workers have in the primary health care sector and in the broader community. Conditions of work must acknowledge this.

6.1.4 Regulation of practice

Legislation covering the practice of Aboriginal and Torres Strait Islander health workers exists only in the Northern Territory. The Working Party sees a need for further debate about the benefits of consistent national workforce legislation. Such legislation, covering all Aboriginal and Torres Strait Islander health workers, could ensure the maintenance of standards of practice for sexual health and other health conditions, thus offering some safeguard to the community. Standards of practice for Aboriginal and Torres Strait Islander health workers are of particular importance for client confidentiality and privacy in relation to STD and HIV testing and treatment.





Research and data collection

7.1 THE THIRD NATIONAL HIV/AIDS STRATEGY

The third National HIV/AIDS Strategy's Research Program, which is funded by the Commonwealth, supports a comprehensive and coordinated program of research designed to increase knowledge about ways of limiting the spread and reducing the harm of HIV. The Program also has a role in providing data for monitoring the effectiveness of recommendations from this report. It seeks to

increase knowledge about ways of eliminating or limiting the spread of HIV infection, of reducing the harm to individuals and the community resulting from HIV infection, and of improving the quality of life of people living with HIV/AIDS. It does this by supporting a comprehensive research program and ensuring that wherever possible research results are acted upon. (Department of Health and Family Services 1996b, p. 58)

The Program is guided by five principles:

- to undertake research within the framework of the Ottawa Charter for Health Promotion;
- to allocate resources according to identified priorities, to areas lacking data, and where the greatest public health benefit can result;
- to concentrate research efforts on providing information about the replication, pathogenesis and transmission of HIV and blood-borne viruses that have a clear and direct impact on HIV progression or transmission so as to facilitate the development of vaccines, immunomodulatory agents and antivirals;
- to give priority to social and behavioural research which has a direct bearing on program and policy planning and management and, where appropriate, involving a partnership approach with the relevant community concerned;
- to use methods appropriate to the area or population under investigation. (pp. 59, 60)

7.2 MATTERS RAISED DURING THE CONSULTATION PROCESS

The last two guiding principles of the Research Program were frequently mentioned during the Working Party's consultations—the need for community

involvement in research, and the use of methods that take into account the range and diversity of Aboriginal and Torres Strait Islander culture. The consultations also confirmed the need for Aboriginal and Torres Strait Islander involvement and control in every stage of the research process, from the determination of priorities and the setting of research questions to the actual carrying out of the research.

Consultations also highlighted the need for mechanisms to ensure Aboriginal and Torres Strait Islander ownership of research data. It was stressed that research methodologies must include strategies to provide researched communities with research results, in a format understandable to community members. Many people also suggested that Indigenous ethics committees could play a key role in ensuring that research is appropriately planned, conducted and reported. Others suggested that there was a need for communities to have access to independent advice about their rights in relation to research conducted in their area.

The Victorian Aboriginal Health Service has established an Institutional Research Ethics Committee to approve and monitor research studies that originate both within and outside the Health Service. The Committee, made up of Aboriginal community members, is registered with the National Health and Medical Research Council and composed according to its guidelines, except that the ‘minister of religion’ is replaced by an Aboriginal elder.

The concerns expressed in the consultations echo concerns expressed in other reports and at conferences. For example, the National Aboriginal Health Strategy and the report of the Royal Commission into Aboriginal Deaths in Custody focussed many of their recommendations on the need for Indigenous involvement in and control of research and the need for the development and use of ethical guidelines. The ‘Anwernekenhe’ Conference stressed the need for the three national HIV research centres—the National Centre in HIV Epidemiology in Clinical Research, the National Centre in HIV Social Research and the National Centre in Virology—to have appropriate Indigenous representation and consultation in their research development.

The Review of Research and Program Findings Relating to the Sexual Health of Aboriginal and Torres Strait Islander People also made specific reference to the need for community involvement in research programs and for community control of decision-making processes connected with research needs.

7.3 RECOMMENDED STRATEGIES

The Working Party is of the view that the greatest public health benefit will come from research processes that are developed collaboratively, between the researchers and the researched. It notes therefore that the following would improve the research effort in Aboriginal and Torres Strait Islander communities:



- Focus the research agenda on managing the transmission of HIV, hepatitis C and related diseases in the context of primary health care settings and in a way that ensures community control.
- Develop Indigenous expertise in the management and monitoring of HIV, hepatitis C and related communicable diseases.
- Give priority to research, particularly social and behavioural research, that will shape the development of sexual health programs.
- The Working Party, in consultation with the Research Advisory Committee of ANCARD, should facilitate discussions in relation to the above.

Using the guiding principles of the third National HIV/AIDS Strategy, the Working Party has identified a number of criteria as important for all research connected with Aboriginal and Torres Strait Islander people:

- Research must be developed in close collaboration with the primary health care sector.
- Research results must be disseminated at the community level.
- Research must be strategically focussed and, in particular, illuminate matters of concern to service deliverers.
- Indigenous health workers and health service managers must have sufficient skill and knowledge to be involved in the projects and research.
- Research must be part of the community development process.
- Researchers must adhere to ethical guidelines—either those established by Indigenous people or the National Health and Medical Research Council’s Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research.

Adoption of these criteria by all research bodies at the local level will mean that sexual health services can develop the most relevant education and prevention and treatment and care programs. It will also mean that State and Territory and national policies are based on accurate knowledge of local and regional needs.

7.4 THE GUIDELINES ON ETHICAL MATTERS IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

The National Health and Medical Research Council’s Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research were developed in response to recommendations of a national conference, Research Priorities in Aboriginal Health, convened by the NHMRC and the Menzies Foundation in Alice Springs in December 1986. The conference organised for a convenor to run a national workshop with a view to producing guidelines on the ethical aspects of research into Aboriginal and Torres Strait Islander health. The National Workshop



of Ethics in Aboriginal Health was convened in August 1987. This meeting drafted a set of advisory notes, which became the NHMRC Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health.

While noting the significant impact of these Guidelines on research into Indigenous health, the Working Party is aware of concern about their coverage and about adherence to them. The Working Party recommends a review of the Guidelines with a view to improving adherence to them and extending their coverage to include all research processes, not just research undertaken through the NHMRC.

The Working Party also recommends that the Australian Health Ethics Committee of the NHMRC promote the establishment of Aboriginal Torres Strait Islander institutional ethics committees.

7.5 RESEARCH INSTITUTIONS

Research institutions will play an important part in facilitating the necessary change in research practice; a collaborative relationship between research institutions and community- controlled health services would be very effective. Examples already exist for a memorandum of understanding between Aboriginal health services and research institutions or researchers; these could serve as a model, outlining roles and responsibilities. In particular, research institutions need to do the following:

- work towards empowering communities to take control of research processes;
- develop protocols for best practice in ‘feeding back’ research findings to communities;
- involve Aboriginal and Torres Strait Islander people in every stage of the research process, including the determining of research priorities and topics;
- establish and use Indigenous ethics committees to examine research proposals;
- ensure that there is appropriate representation and consultation in research development;
- institute appropriate ‘fail-safe’ or contractual agreements to ensure that community wishes are honoured.

The Health Promotion and Research Unit of the Victorian Aboriginal Health Service has developed protocols to facilitate appropriate consultation in the development of research proposals. These include a ‘memorandum of understanding’ to be signed by the researcher and the health service that details responsibilities in relation to ownership and publication of data.



The Working Party should work collaboratively with the HIV social research centres—the National Centre in HIV Epidemiology and Clinical Research, the National Centre in HIV Social Research, and the National Centre in Virology—to advance discussions of ethics and social priorities in connection with Indigenous Australians' sexual health.

7.6 INTERNATIONAL MODELS

At the international level, useful models from Canada warrant further examination. The essence of these models is the formation of strong partnerships between the researchers and the community concerned. This enables community members to make decisions about what information is collected and how it is to be used.

7.7 RESEARCH INTO INJECTING DRUG USE

The Working Party has identified serious deficiencies in research into Aboriginal and Torres Strait Islander injecting drug use. It recommends that action-based research be undertaken in this area. Research into individuals' recruitment into injecting drug use is to receive high priority in the third National HIV/AIDS Strategy; it is important that emphasis be placed on understanding the nature of any increase in injecting drug use in Indigenous communities.

The Working Party stresses that the way in which research is perceived can have a direct impact on people's access to treatment: if people believe their privacy will be invaded if they seek treatment, they are much less likely to seek it. It is vitally important that confidentiality processes in relation to STDs, HIV, hepatitis C and related diseases are adhered to rigorously.

7.8 DATA COLLECTION

Indigenous Australians are very concerned about the use of the word 'surveillance'. To them it suggests government scrutiny of the most personal aspects of their lives. Given the history of relations between Indigenous Australians and their governments, and the particular intrusion on Indigenous people's freedom to choose partners and to bring up their children, this concern is understandable.

The Working Party has decided to use the term 'data collection' in place of 'surveillance', and it recommends that governments consider whether this term is appropriate for their work on the sexual health of Aboriginal and Torres Strait Islander people.

Data-collection systems are used in the health care system to provide an understanding of disease profiles in the community. These systems can play a vital role in telling us where diseases are, which communities are particularly



affected, and how diseases are being spread. They are very important in ensuring that strategies for dealing with HIV/AIDS and related diseases are well directed.

Sexual health data are collected at a range of levels:

- The National Centre in HIV Epidemiology and Clinical Research collects from State and Territory departments of health de-identified data on newly reported cases of HIV and AIDS.
- The National Notifiable Diseases Surveillance System, under the auspices of the Communicable Diseases Network of Australia and New Zealand, monitors the incidence of an agreed list of communicable diseases through national collation of notifications of these diseases received by State and Territory health authorities.
- The States and Territories collect results for some STDs that are notifiable and for HIV and AIDS.
- Some community-controlled health services record local data on the rate of STDs within their communities, to guide their service planning and to monitor the effectiveness of their sexual health programs.

At present, data-collection processes for STDs are inadequate; the most reliable data are available from the Northern Territory and Western Australia.

Data collection remains one of the most controversial aspects of sexual health policy, although there appears to be increasing agreement on the need for data. Fundamental questions remain, however, in relation to collection methods, ownership of information, confidentiality, privacy, access to data, and the ultimate use of data.

Models for data collection—providing, among other things, feedback on data interpretation and establishing links with service delivery—must be established.

7.8.1 Data collection and its impact on the community

Many Aboriginal health services stated in their submissions that communities need to be involved in the development of data-collection systems. This would allow communities to advise collection agencies on the accuracy of the data collected. Confidentiality and privacy were also frequently raised: there is much concern that the community has little or no involvement in how the data are used once integrated into national and State and Territory systems.

Submissions and consultations stressed that data held in State and Territory and Commonwealth health departments should be disseminated to Aboriginal organisations in a format that is understandable and useable. The Working Party is aware of examples of best practice in this area; they could provide useful models for future work.



Data graphics are a graphical way of presenting statistics on STDs to people in remote communities. Developed by Nganampa Health Council and Congress, it does not rely on literacy or numeracy.

Mainstream services also expressed the need for development of standardised monitoring and recall systems. It was noted that a high-quality information system requires participation by individuals, both those seeking treatment and health staff recording the data.

7.9 THE NATIONAL CENTRE FOR ABORIGINAL AND TORRES STRAIT ISLANDER STATISTICS

The National Centre for Aboriginal and Torres Strait Islander Statistics, within the Australian Bureau of Statistics, is examining the question of Indigenous identifiers. In particular, it is working on the assessment and promotion of Indigenous identification in collections. Among its current projects are a catalogue of Indigenous welfare statistics collections; reviews of quality in hospital, cancer and communicable diseases collections; a workshop on improving Indigenous identification in administrative collections; and continuous promotion and evaluation of standard Indigenous identification procedures. The Centre's function is critical for the development of appropriate statistics and information systems for Indigenous Australians.

The Victorian Health Department's Koori Health Unit has developed a best-practice model in accurately recording Aboriginality through two case studies, in Mornington Peninsula Hospital and West Gippsland Hospital. These case studies achieved best practice in a very short time.

The Working Party notes that there are important questions still to be resolved in relation to the use of Indigenous identifiers; the way people are asked about their identity is one question that must be resolved.

7.10 THE NATIONAL COMMUNICABLE DISEASES SURVEILLANCE STRATEGY

The National Communicable Diseases Strategy recommends a range of actions, including the development of a National Communicable Diseases Centre and the implementation of innovative strategies to be developed under the National Public Health Partnership.

7.11 PARTNERSHIP DEVELOPMENTS

Work needs to be done on a partnership basis to reinforce the value of data to the community-based sector in facilitating evidence-based practice: without a partnership built on trust and ethical practice, Aboriginal health services will not value or use sexual health data collected by non-Indigenous and non-local researchers.



The Working Party, through the Department of Health and Family Services, sought information on a range of matters from State and Territory health departments and community-controlled health services. The few Aboriginal health services that responded expressed serious concern about privacy and about how information on sexual health is being used.

Several processes occurring at the national level offer possibilities for progress. The health framework agreements and the National Public Health Partnership will coordinate partnerships with the Commonwealth and the States and Territories. Mechanisms for best practice, protocols and ethical guidelines in relation to data-collection systems are also being developed. Protocols developed within the health framework agreements need to cover the range of agencies that handle data, including private pathology services.

The Aboriginal Health Research Cooperative Ltd in New South Wales is developing protocols for data collection in line with the Aboriginal and Torres Strait Islander health framework agreements.

All levels of government should work cooperatively, with the following aims:

- to develop protocols for data collection, including the cultural protocols and principles encompassed in the National Aboriginal Health Strategy;
- to develop legislative protection of confidentiality;
- to effectively evaluate the process;
- to enable communities to develop at local and regional levels data-collection mechanisms that take account of mobility and cross-border demography and are owned by communities;
- to improve the quality of data-collection through State and Territory governments, the Australian Institute of Health and Welfare, the National Health Information Plan, the National Centre for Disease Control and the National Centre for HIV Epidemiology and Clinical Research.



Evaluation and monitoring

Evaluation and monitoring of the implementation of recommendations from this report will be vital to ensure that effective action is taken which meets the needs of Indigenous Australians.

The following objectives for the evaluation and monitoring of the implementation of recommendations from this report are consistent with those of the third National HIV/AIDS Strategy:

- to measure the performance of strategies outlined in this report in the light of its stated objectives and priorities, at both national and State and Territory levels, with particular reference to effectiveness and cost-effectiveness as measured in terms of outputs and outcomes;
- to provide a mechanism for accountability to all levels of government and other stakeholders;
- to provide a means of communicating to the wider community the successes and the problems and challenges that need to be confronted;
- to ensure that the objectives and priorities outlined in this report are continually informed by the best available social and epidemiological data;
- to meet program managers' and policy makers' need for timely and accurate information on program performance, especially in the context of Commonwealth, State and Territory planning and program management.

The approach to evaluation and monitoring of the third National HIV/AIDS Strategy accords with the processes and principles set out in this report. In particular, the evaluation framework aims to have a high degree of ownership by Indigenous Australians. To achieve this, the evaluation framework will be developed alongside the development of plans for implementation of this report.

This report identifies the fundamental problems that give rise to the poor sexual health of Indigenous Australians. Making the changes needed to redress these problems will take time, and it is reasonable to expect that improvements in the sexual health status of Indigenous Australians will happen slowly. The evaluation and monitoring framework will need to be sensitive to monitoring changes in both sexual health status and health care infrastructure over a lengthy period.

8.1 REPORTING MECHANISMS

Evaluation and monitoring of recommendations from this report will occur in a variety of ways. The primary mechanisms are those outlined in the third National HIV/AIDS Strategy, as follows:

- an annual report to ANCARD by the Indigenous Australians' Sexual Health Working Party, which will form part of ANCARD's annual report to the Minister for Health and Family Services;
- State and Territory governments' monitoring and evaluation of the Strategy's implementation in their jurisdictions (in accordance with the health framework agreements);
- a national program of monitoring and evaluation coordinated by the Public Health Division of the Department of Health and Family Services.

8.1.1 The Indigenous Australians' Sexual Health Working Party

The annual report of the Indigenous Australians' Sexual Health Working Party will review the implementation of those aspects of this report that cannot easily be monitored by the use of social, epidemiological and administrative data; for example, the success of the partnership approach. The Working Party has established a subcommittee in association with the National Centre for Disease Control (within the Department of Health and Family Services) to develop an evaluation and monitoring framework for implementing recommendations from this report.

8.1.2 State and Territory governments

State and Territory governments, in conjunction with Aboriginal community-controlled primary health care services, will be important in the continuing monitoring of services to Aboriginal and Torres Strait Islander people. An important feature of this monitoring will be the State and Territory health forums established under the health framework agreements. State and Territory governments will also ensure that monitoring and evaluation findings are publicly available, and they should collaborate with the Commonwealth and Aboriginal community-controlled health organisations in developing and reviewing performance criteria as part of the Public Health Agreements reached by the Council of Australian Governments.

8.1.3 The Public Health Division

The Public Health Division of the Department of Health and Family Services will manage national monitoring and evaluation in consultation with the States and Territories, the national Research Program, and Aboriginal community-controlled health organisations. There will be three broad areas of monitoring and evaluation activity: the development of a



performance-reporting framework to inform planning and program management; facilitating the use of social, economic and epidemiological data to inform policy and program management; and assessing the efficiency, effectiveness and appropriateness of the response to recommendations from this report, as part of the broader public health system.

The performance-reporting framework will be part of the Public Health Agreements reached by the Council of Australian Governments. These Agreements will need to specify particular performance indicators relating to the sexual health of Indigenous Australians. Continuing monitoring of this report's implementation will focus on prevention, including education. Each State and Territory, and the Commonwealth, should make its performance information publicly available.

The Public Health Division will work closely with the National Centre in HIV Epidemiology and Clinical Research and the National Centre in HIV Social Research to ensure close monitoring of HIV/AIDS, other related communicable diseases such as hepatitis C, and sexually transmissible diseases. Additional evaluation research will be commissioned in epidemiology, economics and social and behavioural research. There will be particular emphasis on improving social and behavioural data on HIV/AIDS, hepatitis C, STDs and sexual health among Aboriginal and Torres Strait Islander people, in keeping with the approach outlined in Chapter 7.

To assess the efficiency, effectiveness and appropriateness of implementation this report's recommendations, as part of the broader public health system, the Commonwealth's efforts in relation to HIV/AIDS, sexual health and related communicable diseases will be evaluated as part of broader evaluations dealing with public health or program structures as a whole.

8.1.4 Important related processes

Continuing evaluation and monitoring of recommendations from this report will depend on work being facilitated through the Office for Aboriginal and Torres Strait Islander Health Services (in the Department of Health and Family Services) to improve the identification of Indigenous people in data collections used by Australian governments. This includes the development of national Aboriginal and Torres Strait Islander health performance indicators and the development for Aboriginal health services of a reporting framework that includes performance indicators.

In February 1996 heads of Aboriginal health units, meeting as a subcommittee of the Australian Health Ministers Advisory Council, were asked to develop broad performance indicators to measure key factors affecting Indigenous Australians' health. This is the first time the Commonwealth and States and Territories have cooperated to develop common ways of measuring their performance in connection with Aboriginal health policy. In February 1997



AHMAC endorsed the indicators. All jurisdictions are to report to AHMAC against these indicators by October 1997.

The subcommittee has developed draft indicators in a number of areas: health outcomes, access to health services, priority health needs, environmental health, workforce development, risk factors, workforce issues, and service outputs.

Alongside this, the Office of Aboriginal and Torres Strait Islander Health Services is currently developing, in partnership with NACCHO and Aboriginal health services, a set of performance indicators that will be used to inform policy and planning in the Aboriginal primary care sector. It is expected that some of these indicators will deal with aspects of sexual health.

8.2 DEVELOPING AN EVALUATION FRAMEWORK FOR THIS REPORT

The Working Party will oversee the development of an evaluation framework for implementing recommendations from this report, in particular being mindful of how current mechanisms can be most effectively used to provide for effective evaluation and monitoring. It is expected that the evaluation framework will facilitate improvements in the quality of epidemiological data by showing where and how the data will be used for the purposes of monitoring and reporting on progress.

An evaluation and monitoring framework will ensure that, as the next level of objectives of this report is developed, these objectives are well understood and there is broad agreement on the criteria to be used to assess performance. Attention will also be given to making sure that evaluation tools such as case studies, data collection and consultation are used in such a way as to contribute to the overall success of implementing recommendations from this report.

The development of such an evaluation framework is a priority for the Working Party upon completion of this report.



Community consultations

Between March 1996 and February 1997 the Working Party held 54 regional Indigenous sexual health consultations across Australia. Among the participants were community elders, representatives of small and large community-based organisations, sexual health workers, representatives of State and Territory government departments, representatives of Aboriginal health services and Aboriginal community-controlled health organisations, prison officers, health care workers, tertiary students and teachers, researchers, representatives of social and welfare organisations, and people living with HIV/AIDS and their families.

The consultations were held in all States and Territories, as follows.

Australian Capital Territory

Canberra Metropolitan Area, 9 August 1996

Queensland

Brisbane Metropolitan Area, 24 and 25 July 1996
Weipa and surrounding areas, 7 and 8 August 1996
Townsville and surrounding areas, 14 and 15 August 1996
Mount Isa and surrounding areas, 21 and 22 August 1996
Rockhampton and surrounding areas, 18 and 19 September 1996
Roma and surrounding areas, 25 and 26 September 1996
Coolangatta-Tweed Heads, 9 and 10 October 1996
Cairns and surrounding areas, 16 and 17 October 1996
Hervey Bay-Sunshine Coast areas, 23 and 24 October 1996
Horn Island and surrounding islands, 1 and 2 May 1996

Victoria

Melbourne Metropolitan Area, 14 and 15 May 1996
Ballarat and surrounding areas, 3 June 1996
Bairnsdale and surrounding areas, 7 June 1996
Echuca and surrounding areas, 28 June 1996

New South Wales

Wagga Wagga and Greater Murray regions, 17 and 18 July 1996
Armidale and New England region, 30 and 31 July 1996
Taree and surrounding district, 5 and 6 August 1996

Moree and surrounding areas, 8 and 9 August 1996
 Narooma and surrounding areas, 21 and 22 August 1996
 Grafton and surrounding areas, 27 and 28 August 1996
 Sydney Metropolitan Area, 5 and 6 September 1996
 AIDS Council of New South Wales, 11 and 12 September 1996
 Griffith and surrounding areas, 17 and 18 September 1996
 Wollongong and surrounding areas, 23 and 24 September 1996
 Mt Druitt, 30 September and 1 October 1996
 Goulburn and surrounding areas, 9 and 10 October 1996
 Lismore and surrounding areas, 15 and 16 October 1996
 Kempsey and surrounding areas, 17 and 18 October 1996
 Dubbo and surrounding areas, 21 and 22 October 1996
 Lightning Ridge and surrounding areas, 24 and 25 October 1996
 Gosford and surrounding areas, 11 and 12 November 1996
 Nowra and surrounding areas, 14 and 15 November 1996
 Broken Hill and surrounding areas, 25 and 26 November 1996
 Campbelltown, 28 and 29 November 1996

Northern Territory

Timber Creek, Bulla Camp, Dagaragu and Kalkaringi, 18–20 November 1996.
 Maningrida outstations, 16 and 17 December 1996
 Oenpelli Community and Croker Island, 18 and 19 December 1996
 Gove, Elcho Island, Milingimbi and Gapuwiyik, 13 and 14 January 1997
 Katherine, 13–16 January 1997
 Borroloola Council, Marbung Association and Rumburriya Council,
 16 January 1997
 Tiwi Island, 19 and 20 November 1996
 Peppimenarti and Port Keats, 13 January 1997
 Alice Springs Metropolitan Area, 19 February 1997

South Australia

Adelaide Metropolitan Area, 10 October 1996

Tasmania

University of Tasmania and Riawunna, 10 May 1996
 South-east Tasmania, 1 August 1996
 West coast Tasmania and surrounding districts, 8 August 1996
 Mersey, Loven, north-west Tasmania and Devonport region, 8 August 1996

Western Australia

East Perth Metropolitan Area, 23 and 24 May 1996
 Albany and surrounding areas, 4 and 5 July 1996
 Bunbury and surrounding areas, 19 July 1996
 Northam and surrounding areas, 9 August 1996
 Kalbarria and surrounding areas, 19 and 20 August 1996



Submissions received

- 1 Academic Unit of Sexual Health, University of New South Wales
- 2 Anyinginyi Congress Aboriginal Corporation, Tennant Creek, NT
- 3 Australasian College of Sexual Health Physicians, Sydney Sexual Health Centre, Sydney Hospital
- 4 Australian Federation of AIDS Organisations Inc.
- 5 ASSENT (AIDS Spiritual Support and Education, NT)
- 6 Astill, Katrina
- 7 Bega Garnbirringu, Health Services Aboriginal Corporation
- 8 Biripi Aboriginal Corporation Medical Centre
- 9 Cleveland Youth Detention Centre, Queensland Corrective Services Commission
- 10 Department of Human Services, Victoria
- 11 Fitzroy Valley Health Service, Fitzroy Crossing
- 12 Geelong Hospital Pathology Service
- 13 Hart, Dr Bret
- 14 Intergovernmental Committee on AIDS
- 15 Kimberley Aboriginal Medical Services Council
- 16 Kunwinjku Language Centre, Kunbarllanjnja
- 17 National Health and Medical Research Council
- 18 New South Wales Health Department
- 19 Nganampa Health Council Inc.
- 20 Royal Perth Hospital, Communicable Disease Service
- 21 Sesnan, Dr Kevin
- 22 South Australian Health Commission
- 23 Streetwise Comics, Leichhardt, New South Wales
- 24 Tri-State STD–HIV Project
- 25 Victorian Deaf Society, East Melbourne
- 26 Western New South Wales Public Health Unit, New South Wales Health Department

APPENDIX C



Media protocols for Indigenous Australians' sexual health

The Working Party is concerned about the way matters associated with sexual health in Indigenous communities, including HIV/AIDS, are dealt with by some mainstream media. Some of the comments made to the media about these matters by public health authorities, the medical profession and the wider health community are also inappropriate.

The following media protocols, or principles, for reporting on Indigenous Australians' sexual health have been developed by the Working Party. These principles will, however, require further discussion with the wider health community to establish agreed principles for media management.

All comments about Indigenous sexual health should be kept as 'general' as possible, with strictly no mention of specific places, communities or individuals.

This principle is particularly important: comments made in the past by health authorities and others, particularly about the incidence of HIV, that have included the name of a locality have inevitably led to media speculation and eventual identification of the Indigenous community concerned. In turn, that community has been able to identify the individual or individuals involved, and their past and present sexual partners.

This has often proved very damaging to particular people, causing some to leave their communities. Such identification of a location has also placed communities under a cloud in relation to the wider community.

If all organisations, particularly public health authorities, adhered to the same principles, much suffering and discrimination in Indigenous communities would be avoided.

In all contacts with the media, respondents should encourage journalists to report responsibly and non-sensationally about HIV/AIDS and other matters connected with sexual health.

People talking to the media, especially the mainstream media, should encourage journalists to treat Indigenous sexual health with respect and sensitivity.

It is preferable to offer an informed Indigenous person as the spokesperson but if this is not possible every effort should be made by the person being interviewed to avoid identification of communities and individuals and to generate discussion in a responsible manner.

It is not suggested that issues be avoided, swept under the carpet or falsely denied; it is simply suggested that efforts be made to restrict comments that would lead to sensational headlines and damaging editorials.

When responding to media inquiries about Indigenous sexual health, try to direct journalists to successful funded projects being undertaken by Indigenous people and health authorities, to give some contrast and balance to a story.

There are many successful sexual health projects operating in Indigenous communities. As long as the project managers have been forewarned and agree to speak with media, promotion of these projects may put a more positive slant on the journalist's story.

Always inform local communities if you have been approached by the media about matters affecting them.

Whenever a media inquiry about sexual health in an Indigenous community is received, the local community should be approached and informed before a formal response is given. Ideally, all comments to the media should avoid specifics, but because this may not always be possible, especially for a public health authority, the people concerned should be consulted and their advice should form part of the eventual response.



Bibliography



- ANCA 1995, *Report on the Aboriginal and Torres Strait Islander Forum on Sexual Health*, Alice Springs, AGPS, Canberra.
- Anwernekenhe Conference Committee 1994, 'Report of "Anwernekenhe": First National Aboriginal and Torres Strait Islander Gay Men and Transgender Sexual Health Conference', Northern Territory.
- Australian Health Ministers Advisory Council October 1994, *National Hepatitis C Action Plan*, AGPS, Canberra.
- Bowden, F.J. & Fairley, C.K. 1996, 'Endemic STDs in the Northern Territory: estimations of effective rates of partner change', Northern Territory RACP Scientific Meeting, Darwin, November, unpub.
- Crofts, N., Stewart, T., Hearne, P., Xin Yi Ping, Breshkin, A.M., & Locarni, S.A. 1994, 'Spread of bloodborne viruses among Australian prison entrants', *British Medical Journal*, vol. 310, pp. 285–288.
- Department of Community Services and Health 1988, *AIDS: a time to care, a time to act. Towards A Strategy for Australians*, Policy discussion paper, AGPS, Canberra.
- Department of Community Services and Health 1989, *National HIV/AIDS Strategy: a policy information paper*, AGPS, Canberra.
- Department of Health and Family Services 1996a, *National Communicable Diseases Surveillance Strategy*, AGPS, Canberra.
- Department of Health and Family Services 1996b, *Partnerships in Practice: National HIV/AIDS Strategy 1996–97 to 1998–99*, AGPS, Canberra.
- Department of Human Services and Health 1993, *The National HIV/AIDS Strategy 1993–94 to 1995–96*, AGPS, Canberra.
- Department of Human Services and Health 1995, *Valuing the Past ... Investing in the Future: evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96*, (Professor R.G.A. Feachem, Evaluator), AGPS, Canberra.
- Grosskurth, H., Mosha, F., Todd, J., Mwijarubi, E., Klokke, A., Senkoro, K., Mayaud, P., Changalucha, J., Nicoll, A., ka-Gina, G., Newell, J., Mugeye, K., Mabey, D. & Hayes, R. 1995, 'Impact of Improved Treatment of Sexually Transmitted Diseases on HIV Infection in Rural Tanzania: randomised controlled trial', *The Lancet*, vol. 346, 26 August.

- Hart, G. 1995, 'Donovanosis in Australia', *Venerology*, vol. 8, no. 2, p. 15.
- McDonald, M-A. 1995, 'Report on Primary Health Care Services in the Torres Strait —An implementation plan', unpub.
- Mitchell, H & Irwig, L. 1991, 'Screening as a Strategy for Disease Control', *Medical Journal of Australia*, vol. 155, pp. 237–40.
- National Aboriginal Health Strategy Committee 1994, 'The National Aboriginal Health Strategy: an evaluation' Department of Human Services and Health, unpub.
- National Aboriginal Health Strategy Working Party 1989, *A National Aboriginal Health Strategy*, AGPS, Canberra.
- National Drug Strategy Committee 1993, *National Drug Strategic Plan 1993–97*, AGPS, Canberra.
- National Health and Medical Research Council 1991, 'Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research,' Draft, NHMRC, Canberra.
- National Health and Medical Research Council 1996b, *Recommendations on Hepatitis Immunisation*, Report by Hepatitis B Working Party, AGPS, Canberra.
- NCHECR 1997, 'National Survey of Hepatitis C prevalence among injecting drug users attending needle exchanges', Sydney.
- Neilsen, G. & Hill, P.S. 1993, 'Human Immunodeficiency Virus Notifications for Aborigines and Torres Strait Islanders in Queensland', *Medical Journal of Australia*, vol. 158, pp.155–7.
- Reid, D. 1996, 'Review of Research and Program Findings Relating to the Sexual Health of Aboriginal and Torres Strait Islander people', Department of Health and Family Services, unpub.
- Scrimgeour, D. 1996, 'Screening Issues for Aboriginal People', in *Central Australian Rural Practitioner (CARPA) Newsletter*, no. 24.
- Torres Strait Health Workshop Working Party Strategy 1993, *Our health, Our future, Our decision: Torres Strait Health Strategy*, unpub.
- Watchirs, H., Reynolds, C., O'Shannessy, L., & Watson, C. 1991, *Legislation Approaches to Public Health Control of HIV-infection*, Paper prepared for the Intergovernmental Committee on AIDS (Australia) Legal Working Party, Department of Community Services and Health, Canberra.



Glossary



Acquired immunodeficiency syndrome (AIDS)

A syndrome defined by the development of serious opportunistic infections, neoplasms or other life-threatening manifestations resulting from progressive HIV-induced immunosuppression.

AIDS councils

Community-based organisations established to provide education, support and care for people infected with HIV or at risk of infection.

Australian Federation of AIDS Organisations (AFAO)

The peak organisation representing State and Territory AIDS councils, the National Association of People with HIV/AIDS, the Australian Intravenous League and the Scarlet Alliance.

Australian Intravenous League

The national organisation representing educational and support groups for injecting drug users.

Australian National Council on AIDS and Related Diseases (ANCARD)

The Commonwealth Government's key advisory body on HIV/AIDS, established to provide independent and expert advice to the Minister for Health on the implementation of the National HIV/AIDS Strategy. It is principally concerned with the identification of national needs, objectives and priorities and takes a public information role on matters associated with HIV/AIDS. It is the successor to the Australian National Council on AIDS.

Australasian Society for HIV Medicine

A society of doctors, scientists and health care workers involved with HIV/AIDS.

Clinical trial

A research activity that is designed to test a drug or treatment to establish efficacy and safety and to identify groups of patients who can be expected to benefit from such drug or treatment.

Communicable disease

An illness caused by a specific infectious agent or its toxic products and that arises through transmission of that agent or its products from an infected person, animal or other reservoir to a susceptible host.

Community care

Care provided in the community as opposed to within an institutional setting. The care may be delivered by professional or volunteer carers, or both, and is often provided in the patient's home.

Community development

An approach to working with the community that aims not only to actively involve the community in dealing with the problem at hand but also to increase the capacity of the community to deal with any future problems that arise. In the specific field of HIV/AIDS such an approach is used to establish community norms and standards that support health-enhancing behaviours.

Culturally appropriate

A term used to describe activities and programs that take into account the practices and beliefs of a particular social group, so that the programs and activities are acceptable, accessible, persuasive and meaningful.

Discrimination, HIV/AIDS-related

Any unfavourable treatment on the basis of known or imputed HIV status; any action or inaction that results in a person being denied full or partial access to otherwise generally available services or opportunities because of known or imputed HIV status. The definition includes discrimination on the grounds of known or imputed membership of certain groups most commonly associated with HIV and AIDS.

Early intervention

An approach to treatment characterised by action in the early stages of a condition; for example, treatment designed to delay the onset of AIDS in an HIV-positive patient.

Epidemiology

The study of the distribution and determinants of health-related states or events in specified populations and the application of this study to the control of health problems.

Gay man

A homosexually active man who identifies himself as gay or is attached to the gay community, or both. Individuals can alter both their self-definition and the level of their community attachment over time. Education and prevention programs typically distinguish between gay men and other homosexually active men.

Health hardware

Applies to the things that are necessary for people to adopt risk reduction behaviours, such as condoms. This concept was developed by Nganampa



Health Council as part of their environmental and public health review within the Anangu Pitjantjatjara lands—*Uwankara Palyanyku Kanyintjaku*.

Health maintenance

Refers to an approach to HIV/AIDS that specifically promotes the benefits of testing for evidence of HIV infection and the subsequent continuing management and monitoring of an HIV-positive person's health with the intention of delaying the onset of AIDS and reducing the severity of AIDS-related illnesses.

High-risk behaviour

see Risk practice.

Homosexually active man

A man who engages in male-to-male sexual behaviour, regardless of whether he identifies himself as gay, heterosexual or bisexual.

Hospital funding grants

Grants provided by the Commonwealth to the States and Territories under the Medicare Agreements to assist in the financing of hospitals.

Human immunodeficiency virus (HIV)

A human retrovirus that leads to AIDS.

Incidence

The number of new cases of a disease in a defined population, within a specified period.

Intergovernmental Committee on AIDS

Provides a forum for regular Commonwealth, State and Territory liaison and coordination on policy, finance, programs and activities related to HIV/AIDS. Membership comprises an independent chairperson nominated by the Australian Health Ministers Advisory Council, two representatives of each of the Commonwealth, State and Territory departments responsible for health, and one representative of each the departments responsible for health in Papua New Guinea and New Zealand. It is now called the Commonwealth–State–Territory Government Forum.

National Association of People Living with HIV/AIDS

The peak national organisation representing people who are HIV positive.

Needle and syringe exchange programs

Authorised programs that distribute, dispose of or sell needles and syringes.



Opportunistic infection

Infection with an organism or organisms that are normally innocuous but that become pathogenic when the body's immune system is compromised, as happens in AIDS.

The partnership

The close working arrangement between Commonwealth, State and Territory and local governments, the affected communities, and the medical, scientific and health care professions that has characterised Australia's approach to the HIV/AIDS.

Peer education

Any education process devised and implemented by members of a population subgroup specifically to alter the behaviours and attitudes of other members of that subgroup; for example, gay men delivering gay education programs.

Prevalence rate

The total number of all individuals who have an attribute or disease at a particular time or period divided by the population risks of having the attribute or disease at this time or midway through the period.

Risk practice

Any behaviour, sexual or otherwise, that is capable of transmitting HIV.

Safe sex, safe sexual practice

Sexual activity in which there is no exchange of body fluids such as semen, vaginal fluids or blood.

Seroconversion

The development of a detectable level of antibodies that occurs after a person has been exposed to and become infected by a micro-organism, such as HIV.

Sex worker groups

Community-based organisations representing people who work in the sex industry.

Surveillance

The continuing scrutiny of all aspects of occurrence and spread of a disease. Its main purpose is to detect changes in trends or distribution in order to initiate investigative or control measures.

User groups

Community-based organisations representing the interests of injecting drug users.



Abbreviations



AFAO	Australian Federation of AIDS Organisations
AGPS	Australian Government Publishing Service
AIDS	acquired immunodeficiency syndrome
ANCA	Australian National Council on AIDS
ANCARD	Australian National Council on AIDS and Related Diseases
ASHM	Australasian Society for HIV Medicine
AusAID	Australian Agency for International Development
CARG	Commonwealth AIDS Research Grants
HIV	human immunodeficiency virus
IDU	injecting drug user
IGCA	Intergovernmental Committee on AIDS
NACCHO	The National Aboriginal Community Controlled Health Organisation
NAPWA	National Association of People Living with HIV/AIDS
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NHMRC	National Health and Medical Research Council
PCR	polymerase chain reaction
PLWHA	people living with HIV/AIDS
SFP	Special Funding Program
STD	sexually transmissible disease
TB	tuberculosis
WHO	World Health Organisation