

“A Response at the Crossroads”

AUSTRALIAN FEDERATION OF AIDS ORGANISATIONS

SUBMISSION

REVIEW OF THE 4TH NATIONAL HIV/AIDS STRATEGY



31 MAY 2002

Australian Federation of AIDS Organisations (AFAO)

- Established in 1986 to represent Australian HIV community based organisations at the national level.
- Membership –
 - State & Territory AIDS Councils.
 - National organisations of people with HIV/AIDS (NAPWA), injecting drug users (AIVL) & sex industry workers (Scarlet Alliance).
- AFAO's work focuses on -
 - HIV policy advice to national government and to community.
 - Skills building activities for HIV educators & other health professionals.
 - HIV prevention and positive education & health promotion campaigns – particularly innovative approaches – with homosexually-active men
 - Work with Indigenous communities with a focus on HIV and sexual health with gay men & transgender/sistergirls.
 - Assisting community groups and governments in the Asia/Pacific region.
 - Vaccines - partner in Australian Vaccine Initiative – Funding from US National Institutes of Health (NIH).
- Funding primarily from Commonwealth Department of Health and Ageing; other sources include US National Institutes of Health; and private donations.

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Scope of this Submission

The objectives and policy principles that have been central to Australia's four National HIV/AIDS Strategies continue to be relevant today. In particular, Australia must continue to pursue the twin goals of –

- Eliminating HIV transmission; and
- Minimising the personal and societal impacts of HIV infection.

AFAO's submission focuses on new efforts needed to translate these goals and the objectives and principles of the 4th National HIV/AIDS Strategy into action. Barriers limiting our progress are discussed and recommendations made to address them. This submission also discusses current and emerging problems in the priority areas identified in the 4th National Strategy - education and prevention; treatment and care; research; sustaining a supportive enabling environment; and international and regional initiatives. Recommendations are made to address problems in these priority areas.

AFAO's submission has a particular focus on the 4th National HIV/AIDS Strategy's framework, structure and mechanisms, where there are several serious problems hampering progress. Recommendations have been made with the aim of generating more effective responses to both HIV and to Hepatitis C.

This submission should be read in conjunction with AFAO's submission to the Strategic Research Review & Review of National & Collaborating Centres in HIV Research.

Executive Summary

Australia's HIV response is at a cross-roads.

It has been largely successful over the last 15 years, characterised by –

- vigorous leadership.
- an effective partnership approach involving government, community, researchers and service providers.
- clear roles and responsibilities.
- program development based on research evidence.
- dedicated funding.

The partnership has fostered an exceptional degree of programmatic integrity across government, community, researchers and service providers – ensuring early and effective response to changes in the epidemic as they have arisen.

This has faltered under the 4th National HIV/AIDS Strategy.

An inter-linked series of factors which shape the impact of the epidemic in Australia are changing. The confluence of these changes has the potential to significantly worsen the epidemic's impact unless effective strategies are put in place soon.

Significant changes are occurring in sexual and social behaviour among homosexually active men, levels of viral load within the community are increasing, antiviral drug treatments are developing more toxicities over time, policy contradictions in the injecting drug area are eroding support for harm reduction principles, the Indigenous communities continue to face a disaster, the research program's future is clouded in uncertainty, and key advisory and decision-making processes are not working.

At the same time we have a burgeoning regional and global HIV epidemic and a rapidly expanding Hepatitis C epidemic in Australia.

Australia's response to both HIV and to Hepatitis C therefore need rejuvenation and substantial re-adjustment if responses to the emerging challenges are to be effective.

The 3rd and 4th National Strategies rolled Hepatitis C into the HIV response. This has not been successful. The real effects have been:

- distracting the Hepatitis C sector from developing the comprehensive range of programs and strategies necessary to combat the Hepatitis C epidemic; and
- distracting the HIV sector from the changing environment and dynamics of the HIV epidemic.

The synergies expected by the drafters of the 4th Strategy have been much less than presumed. In light of the rate of Hepatitis C infections in Australia it is clear that a dedicated, integrated Hepatitis C response, based on the model of the HIV response, should be established immediately.

Australia's HIV and Hepatitis C policy advisory structures have become cumbersome and over-complicated, seriously reducing effective leadership and timely action because of:

- attempting to incorporate both HIV and Hepatitis C – as well as ‘Related Diseases’ - into one structure, namely ANCAHRD and its sub-committees; and
- allocating program implementation and management responsibilities to ANCAHRD, which, as an advisory committee, it is not in a position to fulfil.

The advisory structures should be streamlined. ANCAHRD should be wound up after the expiry of its current term in 2002. The HIV Committee, the Hepatitis C Committee and the Indigenous Australians’ Sexual Health Committee should be established as ministerially appointed advisory committees, with revised terms of reference and clear statements of their role and responsibilities to clarify their relationship to the Minister, the Department and the other members of the Partnership.

The scope of “Related Diseases” in the HIV response should be clarified. This could be done through investigating the feasibility of developing a Sexually Transmitted Infections Strategy during the life of the next strategy.

The HIV Research program is intimately integrated into Australia’s HIV response and its funding and over-sight should remain within the Department of Health and Ageing, with advice from the HIV Committee. Shifting the research program into the National Health and Medical Research Council would seriously reduce the research program’s excellent record in contributing to treatment, care, prevention and policy outcomes for the response in a timely, reflexive and integrated manner.

Changes to health funding and accountability mechanisms from 1996 onwards - particularly the introduction of Public Health Outcome Funding Agreements – have resulted in a substantial loss of accountability for HIV programs and services at State/Territory level. More effective mechanisms must be developed. Meaningful information about HIV programs, services and associated funding is essential to ensure both accountability and the capacity to set benchmarks and standards for the delivery of HIV programs so that implementation can be monitored.

Emerging challenges of the epidemic will require adjustment to funding levels and targets. In real terms, levels of funding for essential activities such as prevention education and HIV research have reduced over time. Community based programs have been particularly affected. The complexity of this work has increased yet this has generally not been matched by appropriate funding.

At the same time, there have been considerable savings in hospital and other care associated costs for people with HIV. This funding has generally not been re-allocated to bolster responses in HIV prevention and other areas of need, but has been diverted to non-HIV health purposes. Priorities set in the HIV strategy – particularly HIV prevention efforts targeting homosexually active men – have not been matched by appropriate funding.

All four national strategies have called for a whole of government approach to HIV/AIDS. Progress has been minimal recently. Effective whole of government responses are even more necessary in light of Australia’s commitments and obligations arising from the regional and international epidemic on one hand, and from our faltering progress in ensuring an enabling legislative environment at both Commonwealth and State/Territory levels on another.

In view of the changes required to rejuvenate Australia’s response to HIV/AIDS - the need to restore focus and to facilitate leadership in that response - AFAO calls for the development of a 5th National HIV/AIDS Strategy to be in place by 1 January 2003.

Recommendations

- *Strategic Framework For Australia's Response To HIV/AIDS*

1. That a continuing high level, dedicated response to HIV/AIDS is required at Commonwealth, State/Territory and community levels.
2. That a 5th National HIV/AIDS Strategy be developed to commence from 1 January 2003.
3. That the following principles and objectives underpin the development of a 5th National HIV/AIDS Strategy:
 - Partnership & leadership.
 - Capacity to act on emerging problems.
 - Clarity on relationships between HIV, Hepatitis C, sexually transmitted infections, sexual health.
 - Clear funding & accountability mechanisms.
 - Appropriate funding levels & targeting.
 - Clear roles for Commonwealth & States/Territories.
 - Effective & clearly defined Commonwealth advisory structures.
 - Sound Commonwealth & State/Territory cooperation.
 - A whole of government approach to HIV/AIDS.
 - Support for community based responses.
 - A response underpinned by research.
 - Meeting obligations under Meeting obligations under the United Nations Declaration on HIV/AIDS & the Asia/Pacific Ministerial Declaration on HIV/AIDS.
4. That separate policy advisory structures be established to support the HIV and the Hepatitis C responses.
5. That a separate funding allocation for Hepatitis C be established to ensure effective implementation of the National Hepatitis C Strategy.
6. That the feasibility of a Sexually Transmitted Infections Strategy be further investigated during the life of the 5th National HIV/AIDS Strategy.
7. That a funding stream be established to address those sexually transmitted infections which do not have a clear and direct impact on HIV transmission and/or transmission.
8. That a formal mechanism be identified in Australia's strategic framework for progressing implementation and monitoring of the UNGASS Declaration of Commitment on HIV/AIDS.
9. That a formal mechanism be identified in Australia's strategic framework for progressing implementation and monitoring of the Asia Pacific Ministerial Statement on HIV/AIDS.

10. That a formal mechanism for promoting a whole of government response to HIV/AIDS be identified and that the Department of the Prime Minister and Cabinet, in consultation with the Departments of Health and of Foreign Affairs, take ongoing leadership responsibility for this.
11. That the Commonwealth work with the States/Territories in formalising a whole of government approach to HIV/AIDS at all levels of government.

- ***National Strategy Roles, Responsibilities, Structures & Mechanisms***

Partnership

12. That guidelines for best practice in actioning a partnership approach be developed. These should define the meaning of partnership as it applies to all parties and should outline the responsibilities of each partner in upholding and implementing a true partnership approach.

Advisory Structures - Australian National Council on AIDS, Hepatitis C & Related Diseases

13. That current advisory structures be restructured to address problems in focus, effectiveness and efficiency.
14. That ANCAHRD and all its sub-committees be wound up and separate, single committees for HIV and for Hepatitis C appointed.
15. That a new Ministerial Advisory Committee on HIV/AIDS be put in place by 1 October 2002, so that it can be involved in the development of the 5th National HIV/AIDS Strategy.
16. That the HIV advisory committee be given a name which appropriately reflects the HIV committee's role and function [eg. "Commonwealth Ministerial Advisory Committee on HIV/AIDS"]. The new HIV advisory committee should be similar in size to the current ANCAHRD HIV sub-committee, with its membership a mix of ex officio and other expert members appointed by the Minister, with the Legal Working Party as its only standing sub-committee.
17. That the Ministerial HIV Advisory Committee's terms of reference no longer designate a formal public information role, but its membership should be used from time to time as appropriate by the government to speak on HIV related issues, as per the model of State/Territory Ministerial HIV Advisory Committees.
18. That the Indigenous Australians' Sexual Health Committee (IASHC) be an independent advisory committee, with close links to the new Ministerial advisory committee on HIV/AIDS.
19. That standard of care protocols and treatment guidelines, and informational materials related to scientific, treatment and infection control issues (including ANCAHRD Bulletins) be developed by the Department of Health or contracted out to appropriate bodies like ASHM and AFAO. Where it is considered appropriate for these publications

to be published by outside organisations, they could also contain endorsement by the Chief Medical Officer of the DHA.

Department of Health and Ageing – Population Health Division

20. That roles and responsibilities between Population Health Division/Department of Health and Ageing and the HIV advisory structures be clarified.
21. That a dedicated HIV/AIDS Section within the Population Health Division be continued for a further period of 5 years.
22. That staffing and other resources within the HIV/AIDS Section be commensurate with the increased complexities of HIV.

States/Territories & Commonwealth Relationships

23. That a full examination be undertaken by all parties of Commonwealth and State/Territory working relationships under the National HIV/AIDS Strategy. The aim should be to identify improved processes for cooperation, coordination and implementation of the National Strategy.

Community Based Response

24. That IGCAHRD and AFAO, in consultation with other relevant community based organisations, review funding levels for community based organisations in light of new challenges and difficulties in responding to HIV/AIDS outlined in this submission.
25. That this process be informed by the development of clear benchmarks and standards for delivery of prevention, education, treatment, care and support services, as well as policy development and advocacy work that is also a key role of a large number of community based HIV organisations.
26. That adequate funding be provided to Scarlet Alliance to allow full participation in the HIV response.

Program, Activity & Funding Accountability

27. That all members of the partnership be involved in developing new mechanisms for HIV funding, accountability, monitoring and evaluation. These should be identified and established by 1 January 2003.
28. That a Commonwealth and States/Territories Matched Funding Program for HIV/AIDS be reintroduced – in particular to cover HIV prevention and related health promotion.
29. That the recommendations of the ANCAHRD HIV Committee relating to mapping HIV related health promotion programs, initiatives and funding targeting homosexually active men be actioned by 1 November 2002, and that establishing related benchmarks be completed by 1 January 2003.

- *Assessment Of Key Areas Of The National Strategy*

HIV Prevention & related Health Promotion

Homosexually active men

30. That action be taken to ensure that programs, activities and funding for HIV prevention and related health promotion targeting homosexually active men is commensurate with the highest priority accorded this group under the 4th National HIV/AIDS Strategy (refer also to recommendations in section 3.6, "Program, Activity and Funding Accountability").
31. That homosexually active men continue to be the highest priority for HIV prevention and related health promotion efforts under the 5th National HIV/AIDS Strategy.
32. That States and Territories immediately collaborate to ensure nationally consistent policies regarding the availability of non-occupational Post Exposure Prophylaxis (PEP), as well as consistent implementation of such policies. Implementation should also include financial support for the promotion of PEP to at risk communities.
33. That the Guidelines for Infrastructure Benchmarks for HIV Education for Gay and Homosexually Active Men be endorsed by IGCARD and that detailed benchmarks for the delivery of prevention and health promotion activities be developed and implemented by all States and Territories.

People who inject drugs

34. That the HIV Committee and HCV Committee jointly develop a position paper advising the Minister on the erosion of harm reduction principles involving injecting drug use and their concerns regarding the impact on public health outcomes. This paper should include specific actions to be undertaken by the Commonwealth and States and Territories, and should be completed by the end of 2002.
35. That the HIV Committee and HCV Committee advise the Minister of the likely impact on public health of the effective obliteration of the non-government Needle Syringe Program outlets and urge a resolution to be sought within the overall negotiations taking place between the government and the insurance industry; and, that the Minister raise this issue with AHMAC with the view to seeking a resolution.
36. That resources for drug user organisations and peer education programs for injecting drug users be reviewed to ensure they have sufficient capacity to combat transmission of both HCV and HIV.
37. That the proposed trial of retractable syringes not be proceeded with.
38. That the Hepatitis C and HIV Committees examine the efficacy of current treatment and support programs for illicit drug users, especially as they relate to blood borne viruses, and develop a plan to address this by 1 June 2003.

Education for People with HIV

39. That program resourcing be reviewed to ensure they are sufficient to meet the increasingly complex demands of providing HIV education and related health promotion for people living with HIV/AIDS.
40. That funding arrangements for community based organisations include flexibility to renegotiate outputs and outcomes to allow for timely responses to changing needs.

Sex Workers

41. That core secretariat funding is provided to the Scarlet Alliance to ensure that national policy development and co-ordination incorporates all members of the Partnership.

Mobility & Migration Issues & HIV/AIDS

42. That issues relating to mobility and migration receive high priority for attention and planning.

Aboriginal and Torres Strait Islander People

43. That the overall policy framework encompassing Indigenous HIV and sexual health issues be clarified and stream-lined during the life of a 5th National HIV Strategy.
44. That the Office of Aboriginal and Torres Strait Islander Health, the National Aboriginal Community Controlled Health Organisation and the AFAO Indigenous Project jointly develop a strategy and allocate resources to refine and expand the HIV and sexual health promotion models developed by AFAO and its members for implementation in all Indigenous communities in all States/Territories.
45. That the HIV Committee and the National Indigenous Sexual Health Committee oversee development of an overall strategy to address the potential impact on the HIV epidemic of cross-border movements along Australia's northern borders.

Treatments

46. That the Minister for Health ensures that any proposed changes to the Pharmaceutical Benefits Scheme do not reduce or otherwise jeopardise the timely and comprehensive access Australians currently have to new HIV therapeutic agents.
47. That the Department of Health & Ageing commission a study on primary care delivery to clarify the challenges to Australia's primary HIV care system and recommend adjustments to ensure standards of care are maintained.

Care and Support

48. That the HIV Committee review the outcomes of the HIV/AIDS General Practice Enhanced Care Demonstration Project and recommend policies and initiatives to be put in place by relevant service providers and government agencies arising from that review.
49. That the HIV Committee undertake a review of the adequacy of mental health services provision to people with HIV/AIDS and those at high risk.

Commonwealth Government's Welfare Reforms

50. That the Government articulate a clear agenda for reform of the welfare system which includes mechanisms for community input into the process.
51. That the special circumstances of HIV/AIDS and other chronic illnesses must also be taken into account, when considering changes to the welfare system.

An Enabling Environment

52. That Commonwealth funding for legal aid be increased for complaints under the *Disability Discrimination Act 1992* so that complainants who cannot afford the cost of legal representation are not denied access to legal remedies for discrimination.
53. That funding be made available for new community education initiatives that promote awareness of anti-discrimination laws, and the remedies such laws can provide.
54. That the Minister for Health, in conjunction with other relevant Ministers, establish and resource a national audit process, as outlined above, to measure each jurisdiction's compliance with the International Guidelines on HIV/AIDS and Human Rights, and to promote reforms which will enhance Australia's enabling environment.

Research

55. That the recommendations contained in AFAO's submission to the Strategic Research Review be adopted.

International & Regional Responsibilities

56. That in light of the burgeoning global epidemic and concomitant threats to economic and political stability, Australia maintain its strong leadership in the global fight against HIV and maximise provision of resources to support this.
57. That more formalised support be given for Australia's contributions to regional and global HIV policy development, including through the work of community based organisations.
58. That lines of responsibility for regional and global HIV policy development in the Commonwealth Government be examined and formalised.

PART I: CONTEXT OF THE REVIEW

1.1 The State of the Epidemic

- *the Global Epidemic*

While Australia's response to the HIV epidemic has been relatively successful to date the global epidemic grows ever more daunting. UNAIDS estimates more than 40 million people living with HIV in 2002, with 5-6 million new infections likely.¹ Three million are expected to die, bringing total estimated deaths from the epidemic to about 23 million.

In the words of UNAIDS, "AIDS has become the most devastating disease humankind has ever faced".

- *the Asia & Pacific region*

Australia lies in the region predicted to become the new centre of the epidemic over the next decade. After a decade of relatively low detected HIV infection rates UNAIDS estimates the Asia Pacific region now has over seven million people living with HIV. Many Asian and Pacific countries have responded only slowly to the challenge of AIDS. It is concerning that the most populous – China, India, Indonesia and Vietnam – are now demonstrating the penalties of this approach: dramatic increases in HIV prevalence in segments of their population which African countries have shown are the harbingers of the transformation to a self-sustaining epidemic among the general population.

Australia bears a special responsibility to its closest neighbour, Papua New Guinea, where the prospects for a devastating epidemic are distressingly high. Its likely impact has been starkly articulated recently in the Centre for International Economics report, *Potential economic impacts of an HIV/AIDS epidemic in Papua New Guinea, (May 2002.)*

In the Asia/Pacific region Australia has a direct national interest in assisting countries reduce the impact of epidemic and a moral responsibility to assist all people with HIV/AIDS and those at risk of infection.

The potential for significant economic loss is high among some of our existing trading partners in the region - and even more so among a number of key partners: China, India and Vietnam. Among the smaller nations the epidemic has the potential to cause not only severe economic declines – requiring additional foreign aid – but also, in the medium-term, political instability in countries such as Papua New Guinea, East Timor, Burma and possibly Indonesia.

Concerted action and leadership by Australia is required if the epidemic in the region is not to significantly impact on Australia's own social and economic health.

- *the epidemic in Australia*

¹ UNAIDS. AIDS epidemic update, December 2001. p.2.

Comprehensive epidemiological statistics indicate Australia has continued to contain the epidemic over the last five years - though a steady rate of infection persists.

The statistics indicate we now about 12,000 people living with HIV – more than at any time previously. The death rate has been declining over the last five years; however, informal indicators suggest this trend is reversing (as it has done in the US).

- ***Homosexually-active men***

HIV infections remain overwhelmingly among homosexually-active men: 77.6% of new diagnoses of HIV in 2001 were attributed to male-to-male sexual contact and a further 4.0% in male-to-male sexual contact with injecting drug use.²

The rate of detected new infections has remained steady in Australia but regional variations remain. For example an increase was reported for Victoria in 2000 and sustained at the higher level for 2001. This rate has remained steady despite significant and continuing increases in the rate of unprotected anal intercourse with both casual and regular partners³ and regular outbreaks of sexually transmitted infections in the gay communities of Sydney, Melbourne and Brisbane.

Australia's steady rate of HIV infection for homosexually active men contrasts with reported increases in this population in comparable countries (Canada, UK, Netherlands). AFAO believes this arises from proportionately more Australians with HIV take treatments, thereby reducing the community viral pool, supported by more sophisticated and sustained transmission prevention education than other countries. This outcome is a direct result of the Partnership approach developed early in the epidemic.

- ***Australia's Indigenous communities***

Infections among Aboriginal and Torres Strait Islander people remain low – notwithstanding Australia's long-standing failure to effectively address the conditions which place these communities at high risk of a rapid increase in infections, including:

- Very high rates of sexually transmitted infections
- Severe social dislocation arising from a long history of institutionalised disruption, discrimination and neglect by both government and the non-Indigenous community
- Significant rates of sexual assault within the community and by outsiders
- Relatively high rates of alcohol abuse and other substance abuse
- Proximity of many indigenous communities to the intensifying regional epidemic in Papua New Guinea and Indonesia

AFAO notes that, given these conditions, the pertinent question is why there has not yet been a substantial increase in HIV infections – and the disturbing answer is that we do not know the answer to this question. Based on experience in the rest of the world - most recently in Asia - the answer would appear to be merely a matter of time unless substantial rapid progress is made to transform the conditions set out above. If recent reports of an apparent increase in HIV infections through injecting drug use among Indigenous people are confirmed then the medium-term outlook appears grim.

² Australian HIV surveillance report, April 2002, p.13

³ Annual report of behaviour, 2001. NCHSR, 2002. p.19

- ***Injecting drug users***

Rates of infection remain very low among injecting drug users. Australia has not seen – yet - the outbreaks that have occurred in some other Western cities.

This success has been due to an extensive and multi-faceted needle & syringe program supported by vigorous though under-resourced peer-based education. However, AFAO notes that changes in Australia's national illicit drugs policies are beginning to undermine the harm reduction foundations of this outstandingly successful strategy (see section 4.1. of this submission).

- ***Sex workers***

Indirect epidemiological data and well-informed reports from community-sector sex worker organisations and sexual health clinics indicate that infection rates for both HIV and other sexually transmitted infections remain notably low among Australia's sex workers.

This is a result of the vigorous work of these two sets of agencies. However, the constantly changing criminal law framework within which the industry operates reinforces the potential for breakdowns of the well-established safe sex culture among sex workers. Sub-populations of concern are street workers and women forced into the international sex-slave trade, predominantly from Asian countries, and forced to operate in brothels often inaccessible to sex worker organisations.

1.2 A Response at the Crossroads

Each National HIV/AIDS Strategy has sets twin goals of:

- eliminating the transmission of HIV; and
- minimising the personal and societal impact of HIV/AIDS.

During the past 15 years Australia has made substantial progress towards meeting these goals. Our response to the epidemic is widely praised internationally. However, there are now clear warning signs that our response is beginning to falter.

Factors which shape the impact of the HIV epidemic are changing in Australia. The confluence of these changes has the potential to significantly worsen the epidemic's impact unless effective strategies are put in place soon.

These confluence of factors are:

- a burgeoning worldwide HIV epidemic, with predictions that Asia/Pacific will become the epicentre of the global epidemic within the decade;
- epidemiological and behavioural data indicating an increased vulnerability to new HIV infections in Australia, especially among homosexually active men;
- eroding support in some quarters for harm reduction approaches, particularly needle and syringe programs;
- limitations of HIV antiviral treatments impacting on care, quality of life, mortality and morbidity, with very few new drugs "in the pipeline" in the short to medium term;
- the substantial problem of HIV antiretroviral drug resistance and cross resistance and treatment related toxicities;
- a larger pool of virus in the community due to changes in antiretroviral treatment guidelines from early to deferred treatment, increasing the potential for HIV transmission;
- ineffective HIV funding accountability mechanisms, program monitoring mechanisms and funding levels to priority areas, particularly HIV prevention targeting homosexually active men;
- an increasingly difficult and complex environment for community based organisations;
- uncertainty and confusion about the future organisation of Australia's HIV research effort;
- questions about the effectiveness of combining HIV and Hepatitis C & Related Diseases policy formulation at the national level;
- an ineffective national HIV advisory structures; and
- increasing complacency and lack of leadership.

AFAO believes we have a relatively brief window of opportunity to respond to these complex difficulties before Australia's HIV response becomes seriously compromised.

We are at a crossroads in our response to HIV/AIDS. Key areas of our National HIV/AIDS Strategy are no longer working effectively. If we fail to act, the consequences will be costly in terms of personal, societal and economic impact. AFAO therefore welcomes the 4th National HIV/AIDS Strategy review as a crucial opportunity to strengthen Australia's capacity to respond effectively to HIV now and in the future.

PART II:

ASSESSMENT OF THE STRATEGIC FRAMEWORK FOR AUSTRALIA'S RESPONSE TO HIV/AIDS

2.1 How the National HIV/AIDS Strategy evolved

A description of how Australia's strategic response to HIV/AIDS has evolved is necessary to put AFAO's submission in context.

Australia's 1st National HIV/AIDS Strategy (1989-1993) formalised a range number of responses at national, state/territory and community levels which emerged as the impact of HIV/AIDS increased through the 1980s. The 1st Strategy was developed after an extensive consultation process. It provided a detailed set of goals, objectives, targets and accountability and evaluation mechanisms. The 1st Strategy also provided several new measures to take the Australian response forward. Some of these were successful and continue today, others were less so. An ambitious program of policy development, leading in some areas to legal changes, was proposed to create a sound environment to enable prevention, care and support to work.

The 1st Strategy was widely regarded as innovative and effective. It was backed up with clearly identified funding itemised for prevention, care and treatment and coordination. The Commonwealth provided stand alone funding for –

- HIV Research (including the national centres for HIV research).
- Programs encouraging innovative approaches at community level, particularly in prevention.
- National Media campaigns to promote HIV awareness.
- National infrastructure to support the Strategy (eg. AFAO, a new advisory structure – the Australian National Council on AIDS [ANCA]).

Additional Commonwealth HIV funding was provided through a matched funding program with the States/Territories. This program offered specific funding allocations to be matched by the States/Territories for –

- HIV education and prevention.
- HIV treatment and services infrastructure
- blood transfusion services
- training (study grants)

The HIV/AIDS matched funding program encouraged efforts from some States and Territories who otherwise may not have responded as effectively. Another benefit of the program and reporting mechanisms was that it gave a reasonably good picture of the range of prevention, education, treatment, care and support, and coordination activities being carried out in cities, outer urban and regional areas. This information assisted a continuing strategic overview and additional responses where needed.

The 2nd Strategy (1993/4 – 1995/6) continued the features of the 1st Strategy with some fine tuning. Through clearer epidemiology HIV prevention efforts were able to be prioritised. Homosexually active men were identified as the highest priority, followed by injecting drug users and their sexual partners. The 2nd Strategy also provided special funds for HIV prevention and care efforts among indigenous communities. The matched funding program with the States/Territories continued. The 2nd Strategy noted that during the life of the previous Strategy there had been a shift in emphasis from national to State/Territory level in direct program planning and delivery. In HIV research, the 2nd Strategy flagged the approach of “mainstreaming” research and called for the gradual transfer of HIV research into Australia’s main research funding body, the NHMRC.

Development of the 3rd Strategy (1996/7 – 1998/9) was informed by the findings of an independent review headed by Professor Richard Feacham⁴. The 3rd Strategy continued the policy and structural framework of previous Strategies, with some notable variations:

- There were no funding details provided in the Strategy document (or breakdown of funding into priority areas) - a significant departure from previous strategies.
- The Commonwealth ended many special purpose payments to the States/Territories, including the matched funding program for HIV/AIDS. These were replaced by broader, outcome based funding agreements between the Commonwealth and the States/Territories (Public Health Outcome Funding Agreements [PHOFAs]).
- The new PHOFAs contained very weak performance indicators for HIV/AIDS. As a result vital information about HIV/AIDS program, activity and funding levels could no longer be obtained.
- The concept of an “HIV, Hepatitis C and related diseases model” was introduced. Some structural changes were made to progress this, including broadened responsibilities for the Commonwealth’s HIV advisory committee (Australian National Council on AIDS [ANCA]). The Strategy provided little detail about the presumed synergies in the “HIV, Hepatitis C and related diseases model” and how the model would operate in practice.
- A reconsideration of HIV research “mainstreaming” and its implications was called for in light of negative effects identified in the Feacham review.

The 4th Strategy (1999/0 – 2003/4) continued the key goals and objectives of its predecessors. However, it also continued the trend of the 3rd Strategy in providing far less detail about how these will be progressed and monitored. Indeed, the 4th Strategy is the shortest document to date.

Other features of the 4th Strategy are:

- An aim to give “clearer expression” to the HIV, Hepatitis C and related diseases model flagged in the 3rd Strategy.
- A large increase in responsibilities for the Commonwealth’s advisory committee - the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) – encompassing advice on HIV, Hepatitis C and related diseases; and reporting on implementation of the National HIV Strategy, National Hepatitis C Strategy and the National Indigenous Australians’ Sexual Health Strategy).

⁴ *Valuing the Past.....Investing in the Future: evaluation of the National HIV/AIDS Strategy 1993/4 – 1995/6*. Australian Government Publishing Service, Canberra.

- Greater sharing of responsibilities between the Department of Health and Ageing (DHA) Population Health Division (PHD) and ANCAHRD than in previous strategies, including a role of “generating rapid and effective responses to emerging changes”. This was something of a departure from relatively clear delineation of roles and responsibilities between ANCAHRD (in providing advice to the Department and Minister) and the Department (implementing decisions of the Minister based on advisory committee advice and its own advice) that characterised previous strategies.

2.2 Does Australia need a National HIV/AIDS Strategy?

Twenty one years after the first public report describing AIDS, twenty years after the first Australian death and four national HIV/AIDS strategies later, it is timely to reconsider the need for a national strategy. This is an obvious starting point for any review.

The question is especially asked by those working in HIV on the ground, where people are focused on local issues - supporting people living with HIV, doing street outreach to those at high risk to HIV infection, or working in an HIV clinic. It is not always apparent in day to day work what a national HIV/AIDS strategy does.

It is also important that the need for a national HIV/AIDS strategy, with its associated effort and cost, be justified to the Australian public.

Based on the problems and challenges described in Part I of this submission, AFAO believes most Australians would support strong action to combat HIV, especially in light of continuing publicity on the epidemic’s toll in the developing world.

In terms of the Australian epidemic, support may well have waned due to relatively low infection rates and the availability of more effective treatments. There is a perception that HIV is “reasonably under control”. However, what is not widely understood is that to keep it under control and to prevent it from worsening, a high level continuing effort is needed. This message has been difficult to convey to the Australian people.

Nevertheless, AFAO believes there is likely to be continuing widespread support among the Australian general public, in government and in community based organisation for continuing efforts to eliminate HIV transmission and care for those living with HIV. However, there will be varying opinions on how this should be done. The question will be asked why HIV requires a dedicated response including a national strategy, rather than being dealt with in the mainstream of the Australian health system.

Some of the reasons in support of a continuing dedicated response to HIV/AIDS are obvious:

- The HIV/AIDS epidemic is out of control in many parts of the world.
- The epidemic is burgeoning in Asia/Pacific.
- HIV/AIDS is not over in Australia – it remains a significant threat. Deaths and new infections continue.
- Those most at risk and infected with HIV are members of marginalized or stigmatised communities
- After 15 years of falling HIV infection rates, Australia has reached a plateau and does not seem able to make further progress in reducing in new infection rates.

- Australian epidemiological and behavioural data indicates an increased vulnerability to new HIV infections, especially among homosexually active men. Similar data is showing up in other comparable countries (eg. USA, Canada, UK), where there are also significant rises in new infection rates.
- Australia has seen a rise in new HIV infections in Victoria during 2000 and 2001.
- Increasing complacency and fatigue about HIV/AIDS, even among communities most affected by the disease, heightening the potential for new infections.

The most effective way of addressing these problems in a decisive, coordinated and cost efficient way is through a national strategy. Planning and implementation through the framework of a national strategy can provide –

- coordinated national and state/territory responses, where bi-partisan political support allows sometimes controversial but necessary measures to be taken.
- best practice standards for prevention, education, treatment, care and support are developed, refined and agreed to nationally and locally.
- Effective use of funding to identified priority areas, based on best practice standards.
- a supportive policy and legal environment agreed to by those with key responsibilities – governments, community based organisations and the health and research sector in particular.

An agreed framework allows people on the ground confidence and support to get the job done.

A nationally agreed strategy can also provide important checks and balances when things go wrong - for example sub-standard services, misdirected funding and emerging threats. Where failings occur at State/Territory, Commonwealth and community levels, a strategy framework helps identify the problem and create pressures and avenues to solve the problem.

We have seen the Australian HIV/AIDS response – and the national strategy in particular – widely cited as a highly successful model to be followed in managing other diseases. Australia has demonstrated that a national HIV/AIDS strategy delivers considerable savings to the health system by preventing new HIV infections. Estimates are that the cost of just one HIV infection in terms of lifelong associated costs is around \$AUD 750,000. Preventing just 100 infections per year covers the total cost of funding provided through the national HIV/AIDS strategy framework for HIV prevention, treatment, care, and research.

Ultimately, the extent of benefits derived from a national HIV/AIDS strategy depends on its content –

- the goals and objectives identified;
- the mechanisms set up for developing policy;
- the mechanisms set up for exchanging information and networking;
- the mechanisms set up for setting standards and benchmarks;
- high quality research to inform responses;
- leadership and commitment from strategy participants;
- communication between key stakeholders;
- communication with affected communities and the Australian public;
- funding and accountability.

How well these components are working is the major focus of AFAO's submission.

Australia's HIV/AIDS response is facing difficult challenges. Our National HIV/AIDS Strategy is not working as well as it should. There may only be a relatively brief window of opportunity to act before our response becomes seriously compromised. Therefore Australia not only needs to continue with a national strategy framework, we also need to bring in a new, significantly strengthened National HIV/AIDS Strategy as soon as possible.

Recommendation:

That a continuing high level, dedicated response to HIV/AIDS is required at Commonwealth, State/Territory and community levels.

That a 5th National HIV/AIDS Strategy be developed to commence from 1 January 2003.

2.3 Australia's next National HIV/AIDS Strategy – Needs, Expectations, Realities

The key step for a rejuvenated nationwide effort against HIV is a new National HIV/AIDS Strategy that reflects a mix of vision and pragmatism. The essential elements of that new strategy should comprise -

- *Partnership & Leadership*

The central platform of the National HIV/AIDS Strategy should be meaningful partnership between governments, communities (particularly those most affected and vulnerable to HIV), and health and research professions. The second key element is leadership, particularly from elected representatives, government officials, community based organisations, and the health sector. Difficult challenges will not be met without leadership. Meaningful partnership and leadership are best supported by effective mechanisms for program and policy development, implementation, evaluation and accountability. The current Strategy has not provided these foundations adequately - so it has been more difficult to provide leadership and to work in partnership. Considerable improvements are needed in the next strategy.

- *Capacity to Act on Emerging Problems*

The current Strategy has not been particularly successful in reacting to emerging problems, primarily because of inherent structural problems and by lack of will. The next strategy must provide a clear plan to address problems in Australia's HIV response. This plan must be informed by and achieve wide agreement from key members of the partnership.

- *Clarity about Relationships between HIV, Hepatitis C, Sexually Transmitted Infections, Sexual Health*

The current strategy attempted to further progress the concept of an "HIV, Hepatitis C and related diseases model". This has not been successful, mainly because the synergies predicted in the 3rd and 4th Strategies were much less than presumed. The next strategy needs to recognise the shortcomings of the current model and ensure there are strong responses to

both the HIV and Hepatitis C epidemics. Better mechanisms must be identified to foster areas of synergy.

- *Clear Funding & Accountability Mechanisms*

Changes to health funding and accountability mechanisms from 1996 onwards - particularly the introduction of PHOFAs – resulted in a substantial loss of accountability for HIV programs and services at State/Territory level. As a result, the current Strategy has been unable to ensure adequate levels of infrastructure and program activity under the Strategy, nor clearly demonstrate value for money due to problems identifying funding streams. More effective mechanisms are needed for the next strategy. Meaningful information about HIV programs, services and associated funding at Commonwealth and States/Territory level is not just about accountability; it is essential for determining benchmarks and standards for the coordination and delivery of HIV prevention, treatment, care and support.

- *Appropriate Funding Levels & Targeting*

In real terms, levels of funding for essential activities like prevention education and HIV research have fallen over the life of the 3rd and 4th National Strategies. Community based programs have been particularly affected. The complexity of our work has increased, especially in prevention and support for those living with HIV, yet this has generally not been matched by appropriate funding.

At the same time, there have been considerable savings in hospital and other care associated costs for people with HIV. This funding has generally not been re-allocated to bolster responses in prevention and other areas of need, but has been diverted to non-HIV health purposes. The priorities articulated in the HIV strategy – particularly HIV prevention efforts targeting homosexually active men – have not been matched by appropriate funding. Funding levels and funding targets are areas that the next Strategy needs to address.

- *Clear Roles for Commonwealth & States/Territories*

Responsibility for most aspects of direct HIV program planning and delivery has now been devolved to the States/Territories. In light of this, the role of the Commonwealth should be clearly focused on –

- coordination and monitoring;
- identifying gaps and emerging problems;
- generating rapid responses where needed;
- commissioning innovative approaches;
- setting standards and benchmarks; and
- supporting research.

The current Strategy defines most of these responsibilities reasonably well, but some additional clarity is needed in the area of standards and benchmarks. The Commonwealth's ability to carry out its responsibilities has been limited by inherent structural problems associated with the current Strategy.

- *Effective & Clearly Defined Commonwealth Advisory Structures*

The Commonwealth's role needs to be informed by expert advice, including an effective advisory structure. Clear delineation of roles and responsibilities (advice vs implementation and management) between advisory committees and the department is essential. The 4th Strategy has not provided an effective advisory structure and has been characterised by confusion in roles between ANCAHRD, the CTARC sub-committee, and the Department of Health and Ageing.

- *Sound Commonwealth & State/Territory Cooperation*

Cooperation between the Commonwealth and States/Territories is again best supported by appropriate structures. In terms of information exchange and implementation, IGCAHRD has been the principal vehicle for this. However, IGCAHRD has been less than effective in this work. The next strategy needs to articulate a better way for the Commonwealth and States/Territories to work together to implement the national strategy.

- *A Whole of Government Approach to HIV/AIDS*

All four national strategies have called for a whole of government approach to HIV/AIDS. Progress towards this has been minimal, particularly during the 4th Strategy. The next strategy needs to put forward concrete measures for fostering a whole of government approach both at Commonwealth and State/Territory levels.

- *Support for Community Based Responses*

The work of community based organisations has been a hallmark of the Australia's response and is internationally recognised. Australian HIV/AIDS organisations are working in an increasingly difficult environment, characterised by current complexities in HIV prevention, care and support which have emerged over the life of the current strategy. More support for community based approaches will result in a more effective HIV/AIDS response.

- *A Response Underpinned by Research*

Australian HIV research is internationally recognised and applauded. Regrettably, the 4th Strategy has been characterised by increasing confusion and uncertainty about the future organisation of Australian HIV research. This has had a demoralising effect. An HIV research program which promotes innovation and provides certainty is crucial to the provision of high quality HIV prevention, treatment, care and support.

- *Meeting Obligations under the United Nations Declaration on HIV/AIDS & the Asia/Pacific Ministerial Declaration on HIV/AIDS*

Australia played a leading role in achieving agreement to both these declarations in 2001. The UNGASS Declaration sets out a list of actions, targets and timelines to be achieved by UN member states. The Asia/Pacific Ministerial Declaration re-iterates commitments made in the UNGASS Declaration and sets forth other actions to be achieved nationally, regionally and globally. The next Strategy will need to identify actions for implementing and evaluating Australia's commitments under both these Declarations. Particular areas for attention will be

generating a more effective whole of government response and more clearly defining our regional and international policy responses.

AFAO has framed its comments on the current Strategy and made recommendations for a 5th Strategy based on the model described above. We believe this model encompasses both vision and pragmatism and would result in a more effective response to the continuing challenge of HIV/AIDS.

Recommendation:

That the following principles and objectives underpin the development of a 5th National HIV/AIDS Strategy:

- Partnership & leadership.
- Capacity to act on emerging problems.
- Clarity on relationships between HIV, Hepatitis C, sexually transmitted infections, sexual health.
- Clear funding & accountability mechanisms.
- Appropriate funding levels & targeting.
- Clear roles for Commonwealth & States/Territories.
- Effective & clearly defined Commonwealth advisory structures.
- Sound Commonwealth & State/Territory cooperation.
- A whole of government approach to HIV/AIDS.
- Support for community based responses.
- A response underpinned by research.
- Meeting obligations under Meeting obligations under the United Nations Declaration on HIV/AIDS & the Asia/Pacific Ministerial Declaration on HIV/AIDS.

2.4 Why incorporating Hepatitis C into the HIV Program has not worked

The policy framework which enabled Australia's successful response to HIV through to the mid-1990s was characterised by –

- clear strategic goals.
- clear delineation of roles and responsibilities among stakeholders.
- a dedicated funding program.
- energetic and innovative program development drawing on a comprehensive and integrated research evidence base.
- bi-partisan political leadership.

The extent of the Hepatitis C epidemic emerged during the 3rd Strategy. Rather than build on the successful model generated for HIV it was decided to in effect “roll” hepatitis C (HCV) into the HIV response along with “related diseases”. While a National Hepatitis C Strategy has subsequently been developed (in 1999), this did not include on-going dedicated funding for HCV programs or research, and it incorporated policy advice into the HIV/AIDS advisory structure.

Thus key elements of the successful HIV model for responding to an emerging epidemic have not been put in place for HCV. This has been a serious shortcoming in public health policy and needs to be rectified.

The rationale for the approach taken (while never clearly articulated) was most often cited as building on presumed synergies and overlap between the HIV and HCV epidemics. Experience has shown that the presumed synergies and overlap are far less than predicted by the drafters of the 3rd and 4th Strategies. Six subsequent years have demonstrated this approach has failed to deliver expected outcomes and has worked to the detriment of both HCV and HIV responses.

The areas of significant overlap are –

- epidemiology and surveillance.
- needle and syringe programs.
- peer education among injecting drug users.

There is some overlap in social research, arising from the marginality of the populations involved, although this is limited. Similarly, providing clinical care has some overlaps although, apart from those with co infection, the more highly dispersed HCV population limits the degree of synergy.

Most of the synergistic benefit has been achieved, although the HCV response would benefit from a substantial expansion of the peer education programs delivered by drug user groups like the Australian Injecting and Illicit Drug Users League (AIVL) and its members.

Both HIV and HCV responses would benefit from a separation of policy advisory structures. Rolling HIV and HCV together has contributed to the dysfunction of current policy advisory bodies (discussed in more detail in section 3.2). The operation of these advisory structures has also been hampered by a failure to develop clear mandates and expectations.

Meetings of the main ANCAHRD and its sub-committee, the Clinical Trials and Research Committee (CTARC), are frustrating for most participants as more than half the business discussed is usually not relevant to them. Lack of clearly designated HCV funding has led to suspicions of funding being directed away from HIV. The “policy-and-funding-fog” in which the advisory structures have been forced to operate has led to undesirable suspicions and tensions between the two sectors, hindering the desired cross-fertilisation of strategies and program development. Fortunately goodwill on both sides has largely avoided potential damage.

There have been two major outcomes from rolling HCV into HIV - both of them undesirable:

- The Hepatitis C sector has been distracted from developing the comprehensive range of programs and strategies necessary to combat the HCV epidemic.
- The HIV sector has been distracted from the changing environment and dynamics of the HIV epidemic.

This has weakened the HIV response at a time of significant change and undermined the development of a comprehensive, integrated HCV response.

We urge the Review to recommend that policy advisory structures and funding streams for the HCV response be disentangled from those with HIV. In those areas of appropriate overlap we

suggest these can be handled through a combination of fixed-term, joint working parties and occasional meetings of the representatives of HIV and HCV advisory committees.

Recommendations:

That separate policy advisory structures be established to support the HIV and the Hepatitis C responses.

That a separate funding allocation for Hepatitis C be established to ensure effective implementation of the National Hepatitis C Strategy.

2.5 HIV, “Related Diseases” and “a broader Sexual Health context”

Experience of HIV/AIDS Community Based Sector

AFAO and our members have longstanding experience working in the area of sexually transmissible infections and sexual health. We have supported allocation of funds to upgrade and extend the sexual health clinic network in Australia, seeing them as integral to the effective response to HIV in Australia.

Moreover, prevention education and health promotion programs delivered by AFAO and our members are set substantially within a sexual health framework. These programs –

- *routinely* provide information on sexually transmissible infections (STIs)
- recommend regular testing for STIs and their treatment (tailored to HIV positive and HIV negative audiences)
- develop and deliver specific campaigns during outbreaks of STIs in relevant communities, and
- conduct self-esteem programs with a particular focus on sexual negotiation and sexual practice.

It is with this experience in mind that we have a strong interest in debates on the strategic frameworks for addressing STIs and sexual health.

Confused Terms & Definitions – 4th National HIV/AIDS Strategy

Part 1 of the 4th National HIV/AIDS Strategy includes a paragraph stating:

The Strategy seeks to give clear expression to the links between the population health responses to HIV/AIDS and a broader range of related diseases, health concerns and sexually transmissible infections, among them hepatitis C and the sexual health of Aboriginal & Torres Strait Islander people”

Later on in other parts of the text the Strategy spells out the proposed links, eg., in research:

[3.4.1] Research into the replication, pathogenesis and transmission of HIV and other viruses that have a clear and direct impact on HIV progression and transmission, to facilitate the development of agents, ...[emphasis added]

Notwithstanding the text of the Strategy, it is not clear what constitutes “related diseases” and the dealing with HIV “in a broader sexual health context”. Confusion has been heightened by ill-defined proposals to incorporate a “Sexual Health Strategy” into the National HIV/AIDS Strategy – or possibly subsume the HIV Strategy into a Sexual Health Strategy.

The proposals range from reproductive health issues through sexual assault and violence to school education curricula. They have enormous programmatic implications. Debate on these proposals has distracted stakeholders from pro-actively and systematically addressing the pressing current issues of the role of sexually transmitted infections in HIV transmission and progression, including:

- increasing outbreaks of sexually transmitted infections among homosexually active men; and
- increasing chlamydia infections in women and men and a lack of clarity about chlamydia’s role in HIV transmission.

Future Strategic Mechanisms

Australia would probably be best served in the long term by the development of three intersecting strategies:

- an HIV Strategy;
- an Hepatitis C Strategy; and
- a newly developed Sexually Transmissible Infections Strategy, which may subsequently develop into a more comprehensive Sexual Health Strategy.

Feasibility of a Sexual Health Strategy

Developing a sexual health strategy would encounter a range of problems. These arise chiefly in clarifying the scope of the strategy and include:

- What are the desired outcomes of national sexual health Strategy?
- Would this strategy target the general population or identify specific population groups, (e.g., indigenous people, sex workers, homosexually active men, young people)?
- Would such a strategy retain the National HIV/AIDS Strategy’s commitment to culturally appropriate education, health promotion and service delivery?
- Would the strategy be disease-focused or a community development model?
- Would the definition of sexual health be multi-layered, broadly based and incorporate the disparate range of sexual health matters that potentially fall within the parameters of a sexual health agenda? For example –
 - fertility and other reproductive health matters.

- sexual violence and assault.
 - school curricula.
 - self-esteem.
 - mental health matters.
 - heterosexism and homophobia
- Who would be the constituents or partners of such a strategy?
 - Who would be responsible for governance of the strategy?
 - Where is the mandate for a sexual health strategy derived from?
 - How is appropriate representation and consultation in the strategy development stage identified?
 - Would such a strategy intersect with the National Indigenous Sexual health Strategy, or subsume it?
 - What funding arrangements currently exist for sexual health programs at State/Territory level and will a mapping exercise of these existing arrangements be conducted prior to developing any strategy?
 - What areas are considered priorities and where and how will resources be targeted?
 - How would the strategy be resourced and what would be the potential impact on currently funded programs including those under the HIV/AIDS strategy?
 - What are the range of political sensitivities that would need to be addressed among other likely stakeholders, both at government level and among community organisations other than those associated with HIV?

AFAO raises these points in order to demonstrate the complexities of developing a Sexual Health Strategy – and partly to explain why previous attempts found it difficult to make progress.

Developing a general population based sexual health strategy requires much more analysis and sharper focus before AFAO could consider supporting it. HIV funding is already compromised by current public health funding mechanisms with the States/Territories and it is likely that any new sexual health strategy would further compromise that funding.

Possible Sexually Transmissible Infections (STIs) Strategy

AFAO would support further work on the feasibility of a Sexually Transmissible Infections Strategy during the timeframe of the 5th Strategy. This would provide an appropriate framework for clarifying those sexually transmitted infections which substantially fit within the ambit set out in the 4th Strategy (eg. gonorrhoea, syphilis, hepatitis A & B) - and those which may have less clear intersection with HIV (eg. chlamydia).

Recommendations:

That the feasibility of a Sexually Transmitted Infections Strategy be further investigated during the life of the 5th National HIV/AIDS Strategy.

That a funding stream be established to address those sexually transmitted infections which do not have a clear and direct impact on HIV transmission and/or transmission.

2.6. Impact of UNGASS Declaration & Asia/Pacific Ministerial Declaration on the Strategic Framework.

2.6.1 UNGASS Declaration of Commitment on HIV/AIDS

The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) was held in 2001. The UN Security Council ordered the special session because of growing alarm at the relentless spread of HIV - which it says is now a fundamental threat to economic and political security and stability – warranting an exceptional and concerted global response.

The UN Special Session was attended by Heads of State and senior Government Ministers from over 100 nations. At the session's conclusion, the UN unanimously adopted a Declaration of Commitment on HIV/AIDS. The Declaration of Commitment is a detailed plan which sets a large number of goals and targets to be achieved from 2003 onwards at national, regional and global levels in four key areas:

- preventing new infections.
- providing care, support and treatment for those infected and affected by HIV/AIDS.
- reducing vulnerability of groups at greatest risk of infection.
- mitigating the social and economic impact of HIV/AIDS.

This submission does not discuss the Declaration's large number of targets and commitments. However, the following selection is provided to illustrate the direct relevance of the UNGASS Declaration to Australia's future HIV strategic response:

Immediate

- develop appropriate monitoring and evaluation mechanisms and instruments to assist with follow up in measuring and assessing progress in implementing the UNGASS Declaration.
- conduct national periodic reviews involving all key stakeholders on progress (in implementing the UNGASS Declaration).
- support and encourage increased national and international investment in HIV/AIDS research.
- integrate HIV/AIDS actions in development assistance programs and poverty eradication strategies and encourage the most effective and transparent use of all resources allocated.
- show leadership in developing regional plans and approaches to address HIV/AIDS.

By 2003

- develop a comprehensive, multisectoral national strategy and funding plan for responding to HIV/AIDS.
- establish national prevention targets, particularly for those at high risk to HIV/AIDS.
- enact legislation and strengthen existing laws where necessary to eliminate all forms of discrimination against people with HIV/AIDS and groups vulnerable to HIV infection.
- have in place strategies, policies, programs, actions, and set targets for achievement that identify and begin to address those factors that make individuals particularly vulnerable to HIV infection, including economic insecurity, poverty, lack of adequate information, discrimination, and lack of information and/or commodities for self-protection (condoms, safe injecting equipment, etc).
- review and evaluate the economic and social impact of the HIV/AIDS epidemic and address special needs.

By 2005

- ensure availability of comprehensive prevention programs which target all sections of society, particularly those at high risk to HIV/AIDS.
- strengthen the response to HIV/AIDS in the workplace.
- develop and implement strategies to facilitate prevention programs for migrants and mobile workers.
- ensure that at least 90% of young people have access to HIV education and other services to develop life skills to reduce their vulnerability to HIV infection

Currently, there is no mechanism identified in the Australian strategic framework to take responsibility for progressing implementation and monitoring of the UNGASS Declaration.

Australia played a key leadership role in negotiating agreement to the UN HIV/AIDS Declaration. Given this, many nations will expect Australia to show strong leadership in implementing the Declaration nationally, regionally and internationally. It is therefore essential that Australia's future strategic framework for responding to HIV - including the next HIV strategy - reflects the commitments we have agreed to in the UN Declaration.

Recommendation:

That a formal mechanism be identified in Australia's strategic framework for progressing implementation and monitoring of the UNGASS Declaration of Commitment on HIV/AIDS.

2.6.2 Asia Pacific Ministerial Statement on HIV/AIDS

Ministers from countries of the Asia-Pacific region met in October 2001 at the initiative of the Hon. Alexander Downer MP, Minister for Foreign Affairs "*to consider the significant challenges the HIV/AIDS epidemic poses and to identify ways to strengthen partnerships to combat the devastating spread of HIV/AIDS*". The Asia/Pacific Ministers adopted a Statement which "*recognises that strong leadership and political commitment at the highest levels is vital to achieving this goal*".

The Statement's commitments include undertakings to -

- achieve all targets in the Declaration of Commitment on HIV/AIDS adopted by the United Nations General Assembly.
- address the social and economic contributing factors and impact of the HIV epidemic.
- address the impact of HIV on security, through enhanced coordination and strengthened partnerships at the community, national, cross-border and regional level.
- encourage the further development of multi-sectoral, national plans of action and sub-regional and regional initiatives to address HIV/AIDS.
- encourage the strengthening of national and regional partnerships incorporating governments, the private sector, the medical and scientific community, community groups (particularly of the most vulnerable groups) and international organisations, including south-south cooperation.
- develop an Asia-Pacific Leadership Forum on HIV/AIDS with establishment support from Australia.
- enhance national financial mechanisms so as to better attract and coordinate domestic and international resources for action against HIV/AIDS.
- meet again in 2003 in Australia to review progress to combating the growing impact of the epidemic across the Asia-Pacific region.

Like the UNGASS Declaration, the Asia Pacific Ministerial Statement on HIV/AIDS contains commitments which Australia will be expected to meet - especially as we organised the event and have undertaken to do so again in 2003. As for the UNGASS Declaration, it is important that the Australia's future strategic framework for responding to HIV - including the next National HIV Strategy - reflects the commitments we have agreed to under the Asia/Pacific Ministerial Statement.

Recommendation:

That a formal mechanism be identified in Australia's strategic framework for progressing implementation and monitoring of the Asia Pacific Ministerial Statement on HIV/AIDS.

2.7 Promoting a Whole of Government Approach to HIV/AIDS

HIV is not just an issue for health departments – many other areas of government need to contribute towards Australia's HIV response. The promotion of a "whole of government" approach to HIV has been a central theme of all Australia's National HIV/AIDS Strategies. The UNGASS Declaration of Commitment also lists this as a key measure for effective national responses.

Achieving an effective whole of government approach is a difficult challenge. Australia has not done particularly well in this area, especially during the 3rd and 4th Strategies.

A better way of promoting whole of government responses to HIV needs to be found. A first step should be to identify a formal mechanism and plan to engage government. Leadership by the Department of the Prime Minister and Cabinet (or possibly the Department of Foreign Affairs) in consultation with the Department of Health may be the best way of promoting an effective whole

of government response and for monitoring implementation of the UNGASS Declaration across government and nationally.

Recommendation:

That a formal mechanism for promoting a whole of government response to HIV/AIDS be identified and that the Department of the Prime Minister and Cabinet, in consultation with the Departments of Health and of Foreign Affairs, take ongoing leadership responsibility for this.

That the Commonwealth work with the States/Territories in formalising a whole of government approach to HIV/AIDS at all levels of government.

PART III: ASSESSMENT OF NATIONAL STRATEGY ROLES, RESPONSIBILITIES, STRUCTURES & MECHANISMS

3.1. Partnership

Working in partnership has been the foundation of Australia's approach to HIV/AIDS. The 4th Strategy lists partnership as a central element of our response and describes it as being "*based on a commitment to consultation and joint decision making in all aspects of the response*".

Considerable strength remains in the partnership, and there are areas where partnership has been enhanced during 4th Strategy (for example between community and researchers). However, in other areas there are signs of waning commitment to maintaining the principles of collaboration and partnership.

Some participants in the partnership have tended to take a minimalist approach, involving the community sector – and sometimes other partners - only when it is unavoidable, rather than consistently as a matter of principle. This has undermined confidence within the community sector about the level of commitment to meaningful partnership.

The frequent turnover of key staff within government Health departments contributes to a dilution of partnership principles being consistently put into practice, as new staff may not be used to working in this model.

Another area where the principle of partnership has been missing is the National Public Health Partnership (NPHP) and the Public Health Outcome Funding Agreements. The NPHP has a direct impact on Australia's HIV response, but the mechanisms to involve community are minimal and the community has been excluded from decision making processes.

Partnership is a valued principle of Australia's HIV response. However, there has been some disengagement from genuine, practical and routine implementation of that principle. AFAO recommends that guidelines for best practice in actioning a partnership approach be developed. These should define the meaning of partnership as it applies to all parties and outline the responsibilities of each partner in upholding and implementing a true partnership approach.

Recommendation:

That guidelines for best practice in actioning a partnership approach be developed. These should define the meaning of partnership as it applies to all parties and should outline the responsibilities of each partner in upholding and implementing a true partnership approach.

3.2. Advisory Structures - Australian National Council on AIDS, Hepatitis C & Related Diseases (ANCAHRD)

Introduction & Background

Effective structures to provide the government with expert, independent advice are essential to a successful response to HIV/AIDS. Advisory structures at national and State/Territory levels should continue to play an important role in monitoring trends, identifying problems and recommending action.

Over the past 15 years changes have been made to Commonwealth HIV advisory committees designed to have structures, membership, roles and responsibilities appropriate to the times.

The Commonwealth Health Minister set up formal committees to advise the government on HIV policies and priorities in 1985. In 1988 these committees were amalgamated and became the Australian National Council on AIDS (ANCA).

The early years of the epidemic were characterised by considerable misunderstanding about HIV in the Australian community, and at times hysterical coverage by the media. The Commonwealth government, with support from community based organisations, used ANCA not only to advise on policies and priorities, but also as a vehicle to educate the Australian community. A high profile Australian, Ita Buttrose, was asked to lead ANCA. As chair, Ms Buttrose, along with other ANCA spokespersons effectively promoted community awareness about HIV, using the name of “ANCA” as a vehicle for this work.

Adding ANCA’s name to potentially controversial HIV awareness messages and campaigns was also seen by some as useful in providing “distance” between these campaigns and the Commonwealth government. However, this benefit was always debatable and is certainly much less tangible today - especially as the Commonwealth has moved away from substantial media campaigns such as the “Grim Reaper” and national HIV anti-discrimination campaigns of the late 1980s and early 1990s.

ANCA performed well in its core function of providing policy and priority advice to government. However, at times it lost focus and its structure became too complex and membership too large. It was reconstituted a number of times to promote effectiveness.

ANCA replaced by ANCAHRD

ANCA was replaced by a new ministerial advisory committee in 1996 to coincide with the release of the 3rd Strategy. The new committee’s brief was considerably widened to cover not only HIV but also “related diseases”, principally Hepatitis C. The committee’s current name - the Australian National Council on AIDS, Hepatitis C & Related Diseases (ANCAHRD) - reflects this broader brief.

ANCAHRD has a complex structure. It comprises an over-arching committee (ANCAHRD), an executive, and three sub-committees –

- The HIV Committee
- The Hepatitis C Committee
- The Clinical Trials and Research Committee

Additionally, there are ongoing working parties to cover legal issues and vaccines. The Indigenous Australians' Sexual Health Committee (IASHC) also reports to ANCAHRD.

ANCAHRD members are appointed by the Minister for Health. Sub-committee members are primarily appointed by the ANCAHRD chair, with some additional ex-officio members (including the Australasian Society for HIV Medicine, AFAO).

ANCAHRD's Responsibilities & Performance

The first three National Strategies assigned responsibilities to the Ministerial advisory committee which were mostly appropriate and consistent with the role of an advisory committee – providing expert advice, rather than becoming involved in implementation and management.

However, the 4th Strategy saw several new responsibilities added to ANCAHRD's brief, some of which are neither appropriate nor achievable for an advisory committee (refer Appendix A). Perhaps the most anomalous of these relates to implementation of the 4th Strategy. Here it states that *“The National Strategy will be put into effect through the work plans of the ANCAHRD and its committees.”* The Strategy does not explain what this statement means and how it should occur. As a result, implementation has been poor. Implementing HIV strategies and policies is a task for government departments, along with key parties like community based organisations, health and scientific bodies - governments should not devolve this role to advisory committees.

ANCAHRD's role is appropriately one of commenting on implementation plans, reviewing progress, identifying barriers and proposing solutions to the Department and Minister for consideration.

As mentioned earlier, ANCAHRD's role now covers not only HIV but also “related diseases”, principally Hepatitis C. Experience has shown that overlap between HCV and HIV is significantly less than presumed under the 3rd and 4th Strategies. Therefore the main ANCAHRD committee's task of dealing with HIV, HCV and “related diseases” is very difficult - the responsibilities far too broad and the areas lacking in sufficient synergy. These factors have contributed to ANCAHRD's increasing dysfunction.

ANCAHRD has not been able to provide effective advice on several serious problems and challenges impacting on the Australian response to HIV/AIDS. These include recommending strategies to address –

- ineffective mechanisms for implementing and monitoring the National HIV and Hepatitis C Strategies.
- ineffective HIV funding accountability mechanisms, performance indicators, program monitoring mechanisms and funding levels to priority areas, particularly HIV prevention targeting homosexually active men;
- epidemiological and behavioural data indicating an increased vulnerability to new HIV infections in Australia, especially among homosexually active men (eg. Victorian 2000 and 2001 HIV infection rates);
- confusion about the future organisation and funding of HIV/AIDS and Hepatitis C related research.

- the need for further responses to the burgeoning regional and global HIV epidemic, especially in light of the potential for significant societal, economic and political destabilisation.
- lack of effective mechanisms for monitoring implementation of the UNGASS Declaration of Commitment on AIDS and the Asia/Pacific Ministerial Statement on AIDS.
- lack of an effective whole of government response to HIV.
- ineffective mechanisms to support HIV vaccine policy and development.
- insufficient focus on Hepatitis C by Australia's political leaders and general community.

Specific advice and recommendations have been made on a number of these and other issues by the ANCAHRD sub-committees. However, it has been difficult for ANCAHRD to deal with these recommendations, mainly because of inherent structural problems.

One area in which ANCAHRD became extensively involved was HIV research organisation and funding. AFAO's criticisms of ANCAHRD's handling of HIV research, including interactions with the National Health and Medical Research Council and confusion over roles and responsibilities vis a vis the Department of Health and Ageing, are described in our submission to the Strategic Research Review, and elsewhere in this submission. The future of HIV research remains unresolved.

The workplans and annual reports produced by ANCAHRD have consumed large amounts of time and resources. However, outcomes have been modest. The ANCAHRD workplans and annual reports have not focused strongly enough on overseeing progress in implementing the National Strategies and proposing actions to deal with emerging threats and challenges.

The operating costs of ANCAHRD, its sub-committees and working parties, costs associated with chairs and members, publication costs, etc, are considerable (approximately \$0.6 million). ANCAHRD's outcomes do not justify this level of expenditure. Further, ANCAHRD's servicing requirements place a heavy workload on limited staffing and other resources of the Population Health Division of the Department of Health and Ageing (this has not been costed).

AFAO does not question the dedication and commitment of members of the overarching ANCAHRD committee. However, the reality is that the main ANCAHRD Committee's membership collectively lacks sufficient expertise to deal with ANCAHRD's vast brief of covering both HIV and Hepatitis C and "related diseases". To do this would require a very large number of expert members, which would make the committee's functioning unmanageable.

ANCAHRD's Public Role & Profile

ANCAHRD's public profile is low, as were its predecessors from the early 1990s onwards. It is likely that the public does not differentiate ANCAHRD from several other HIV specific organisations, including AFAO, ASHM, AIDS Councils, the AIDS Trust of Australia, etc. Indeed, the review of the 3rd Strategy noted comments that ANCAHRD did not have a high profile even among people involved in HIV/AIDS, Hepatitis C and sexually transmissible diseases outside Sydney.

The time for a high profile HIV national advisory committee has passed. Public leadership on HIV/AIDS is now best delivered by:

- the Health Minister and other appropriate government Ministers;
- key politicians through a bi-partisan approach;
- senior officials (particularly Chief Health Officers);
- HIV/AIDS community based organisations; and
- health profession and research organisations (eg. Colleges, ASHM, National HIV Centres).

It can be useful from time to time for governments to ask advisory committee members to promote HIV awareness in the media and other forums on particular issues (indeed the NSW and Victorian Ministerial advisory committees work quite well in this regard). Where this occurs, a title like “Ministerial Advisory Committee on HIV” conveys more clarity than use of “Council”.

Information, Protocols & Guidelines

Promulgating the results of research and reflecting research findings in protocols and guidelines is an important function. ANCAHRD has some responsibilities in this area, but its performance has been problematic. Recent efforts by ANCAHRD to develop public informational bulletins on Infection Control in Sport, and Blood Borne Viruses in the Home are illustrative of operational problems. The sport bulletin was issued with a “two bleeds and you are out” rule which has no scientific basis. The blood borne viruses bulletin went through so many drafts its original purpose could no longer be recalled.

The role of the Ministerial HIV advisory committee should be to identify gaps in information, protocols and guidelines and to comment on drafts where appropriate. The Department of Health and Ageing should take responsibility for production of standard of care protocols and treatment guidelines based on research findings, as well as informational materials related to scientific, treatment and infection control issues (including Bulletins). These publications should be developed by the Department itself or contracted to appropriate bodies like ASHM and AFAO. Where it is considered appropriate for these publications to be published by outside organisations, they could also contain endorsement by the Chief Medical Officer of the Department.

ANCAHRD’s HIV Committee & Hepatitis C Committee

The HIV Committee works well with effective meetings and worthwhile outcomes. Its problem is it sits within an overly complicated structure.

The HIV Committee’s members contain a balance of ex officio appointees from peak NGOs, plus a range of experts directly involved in the HIV covering medical, scientific and community areas. The committee has used the model of short term, outcome focused working parties to address specific issues, bringing in outside expertise where needed. In addition to its current advisory responsibilities, the HIV Committee is well placed to provide advice on HIV treatment and care issues and on research.

AFAO favours a model similar to the current HIV Committee as the advisory structure for the remainder of the 4th Strategy and for a 5th Strategy.

AFAO’s experience of the ANCAHRD HCV Committee is more limited, but our Hepatitis C community sector colleagues tell us it also works reasonably well, in a similar manner to the HIV Committee.

ANCAHRD's Clinical Trials & Research Committee (CTARC)

ANCAHRD and CTARC have largely failed to provide effective oversight and co-ordination of Australia's research program as proposed in the 4th Strategy. A climate of confusion exists because clear boundaries have not been maintained between the advisory role of committees like CTARC and the implementation and management role of the Department of Health and Aging. This has been compounded by systemic and structural issues, chiefly arising from a fundamental problem: moves to roll together HIV and HCV research under the 4th Strategy.

Rather than beneficial synergies that were hoped for in this move the results have in fact been:

- lack of clarity about the role of CTARC.
- developing cynicism among CTARC members.
- a very large body, where much of CTARC's business is not relevant to half or more of the meeting participants at any one time.
- cumbersome decision-making, with an understandable tendency for decisions to be made outside this forum.
- micro-management of the National HIV Research Centres' workplans, further confusing the Centre Directors and their scientific advisory committees.
- lack of sufficient focus on the big picture issues in Australia's research program.
- confusion and frustration among all stakeholders.

The outcomes have not been beneficial for either HIV or HCV research. Centre Directors have been distracted from core business attempting to develop some HCV "synergistic" projects – where experience has demonstrated that, except in surveillance, these synergies are minimal. For HCV community representatives and researchers, CTARC has proved at best marginally useful for advice. Its greater impact has been an unintended distraction from developing a more strategic approach towards establishing a clear program and funding base for HCV research.

A streamlined advisory structure is needed to provide effective advice on HIV and HCV research. The overarching ANCAHRD committee and CTARC should be abolished, and the HIV Committee and the HCV Committee retained and given responsibilities for research oversight. They are capable of handling this task effectively. The HIV Committee and the HCV Committee would provide broad oversight and advice on National Research Centre programs, but the Centre's primary responsibilities and performance would be managed through their contracts with the Department of Health and by reporting to their Scientific Advisory Committees.

With the considerably improved functioning of the Research Centre Scientific Advisory Committees, the task of approving individual research proposals (particularly clinical research studies), currently vested in CTARC, can be devolved to the Scientific Advisory Committees.

Future Advisory Structure

Australia's HIV/AIDS response is being unintentionally hampered by the large number of roles, responsibilities and tasks currently assigned to ANCAHRD. A number of these tasks are inappropriate for an advisory committee. This has created unreasonable expectations that such tasks and responsibilities could be delivered on - resulting in frustration among stakeholders when they are not. Inappropriate assignment of responsibilities and tasks to ANCAHRD is discouraging other parties - particularly the Population Health Division of the Department of Health and Ageing - from focusing more on implementing the National Strategy and addressing

other problems. There is an urgent need to correct this situation. National advisory structures should have clear, realistic and appropriate roles and responsibilities, so Australia is better placed to respond to HIV.

ANCAHRD should be restructured to address problems in focus, effectiveness and efficiency.

The current ANCAHRD should be wound up when its term ends in August 2002. Separate, streamlined and focused advisory committees for HIV and Hepatitis C should be appointed as a matter of urgency. Consistent with the continuing threat from HIV nationally, regionally and globally, the new HIV committee should be an independent, expert based committee advising the Health Minister directly. The same model should be used for Hepatitis C.

Suggested terms of reference for a new Commonwealth Ministerial HIV advisory committee are:

To advise the Minister for Health on the HIV/AIDS epidemic, including:

- *national needs, objectives, priorities and progress in implementing the National HIV/AIDS Strategy;*
- *actions to address emerging issues and changes in the epidemic; education priorities, the treatment and care of people living with HIV/AIDS, and strategies for the prevention of HIV/AIDS;*
- *medical, scientific, research, ethical, legal, social and public health responses to HIV/AIDS;*
- *processes for setting standards and benchmarks for the delivery of prevention education, treatment, care and support;*
- *region and international responses to HIV; and*
- *other matters referred to it by the Minister.*

AFAO proposes that the membership of this committee, with the suggested title "Commonwealth Ministerial Advisory Committee on HIV/AIDS" (CMACA), be similar in size to the current HIV Committee membership which is a mix of ex officio and other expert members appointed by the Minister. The CMACA should meet 4 to 6 times per year. Small, short term, fixed outcome working parties should be used where needed to progress the CMACA's work.

There should be no standing sub-committees, except for the Legal Working Party. This sub-committee should continue as an important forum for progressing efforts in the legal area. The Indigenous Australians' Sexual Health Committee (IASHC) should become an independent advisory committee, with close links to the new Ministerial advisory committee on HIV/AIDS. The Vaccines Working Party should be replaced by a new initiative - the Australian HIV Vaccine Initiative (AHVI) - to be auspiced through the National Centre for HIV Epidemiology and Clinical Research (refer AFAO's submission to the Strategic Research Review).

The new advisory structure should be in place by 1 October 2002 so that it can be involved in the development of the 5th Strategy.

An annual report should be made to the Minister which specifically addresses progress made for each of these terms of reference. The Parliamentary Liaison Committee should be briefed on the report.

In those areas where there is clear overlap between HIV and Hepatitis C, joint working parties should be established from time to time to work on issues of mutual concern. Both committees should keep each other informed by exchanging minutes and other means. There is a clear role for the DHA in progressing those synergies in Hepatitis C and HIV that do exist.

The above processes should be used for other policy areas where there are overlaps and synergies.

Recommendations

That current advisory structures be restructured to address problems in focus, effectiveness and efficiency.

That ANCAHRD and all its sub-committees be wound up and separate, single committees for HIV and for Hepatitis C appointed.

That a new Ministerial advisory Committee on HIV/AIDS be put in place by 1 October 2002, so that it can be involved in the development of the 5th National HIV/AIDS Strategy.

That the HIV advisory committee be given a name which appropriately reflects the HIV committee's role and function [eg. "Commonwealth Ministerial Advisory Committee on HIV/AIDS"]. The new HIV advisory committee should be similar in size to the current ANCAHRD HIV sub-committee, with its membership a mix of ex officio and other expert members appointed by the Minister.

That the Ministerial HIV Advisory Committee's terms of reference no longer designate a formal public information role, but its membership should be used from time to time as appropriate by the government to speak on HIV related issues, as per the model of State/Territory Ministerial HIV Advisory Committees, with the Legal Working Party as its only standing sub-committee.

That the Indigenous Australians' Sexual Health Committee (IASHC) be an independent advisory committee, with close links to the new Ministerial advisory committee on HIV/AIDS.

That standard of care protocols and treatment guidelines, and informational materials related to scientific, treatment and infection control issues (including ANCAHRD Bulletins) be developed by the Department of Health or contracted out to appropriate bodies like ASHM and AFAO. Where it is considered appropriate for these publications to be published by outside organisations, they could also contain endorsement by the Chief Medical Officer of the DHA.

3.3. Department of Health and Ageing – Population Health Division

The Population Health Division (PHD) has a key role to play in implementing the National HIV Strategy at Commonwealth level and in coordinating responses at State/Territory levels. The PHD's other core function is providing expert advice on HIV to the Minister, along with the ministerial advisory committee.

The HIV/AIDS Section of the PHD is the focal point for this work. The HIV/AIDS Section also administers a number of grants aimed at fostering national coordination and manages the HIV/AIDS research program.

Given the current challenges and complexities in HIV/AIDS, there is a strong case to continue with a dedicated HIV/AIDS Section within PHD.

AFAO has an effective working relationship with the PHD. We value the dedicated efforts of the PHD, and in particular officers of the HIV/AIDS Section with whom we have substantial interactions.

As discussed elsewhere in this submission, there are serious structural problems in Australia's national HIV response which restricts the PHD from performing core work of Strategy implementation, coordination and program management. In particular, there is confusion in roles and responsibilities between ANCAHRD and the PHD vis a vis providing advice, and implementation and management. The HIV research program is a clear example of this confusion. These problems must be addressed to better enable the PHD to carry out its core work in HIV/AIDS.

While complexities and challenges in HIV have grown over the past five years, resourcing of the HIV/AIDS Section has not increased commensurately. This has made it very difficult for the Section to manage its functions and responsibilities in HIV, particularly in areas like research. It is important that this situation be addressed.

Recommendations:

That roles and responsibilities between Population Health Division/Department of Health and Ageing and the HIV advisory structures be clarified.

That a dedicated HIV/AIDS Section within the Population Health Division be continued for a further period of 5 years.

That staffing and other resources within the HIV/AIDS Section be commensurate with the increased complexities of HIV.

3.4. States/Territories & Commonwealth Relationships

The States and Territories now have major responsibility for delivery of programs and services, following devolution over the past several years.

However, during the life of the 3rd and 4th Strategies the mechanisms for tracking delivery of HIV specific services and related funding have become inadequate or non-existent in most States/Territories, especially at regional and local levels. Most of the States/Territories are unable, or in some cases, unwilling, to provide adequate information about programs, activities and funding. It is therefore impossible to properly assess if priorities identified under the National Strategy are being met.

A key example of this is information about activities, programs and funding for HIV related health promotion among homosexually active men (identified as the highest priority for effort under the 4th Strategy).

These accountability problems are discussed at length in section 3.6 (Program, Activity & Funding Accountability).

The States/Territories and the Commonwealth have not worked as effectively together during the 4th Strategy, as in previous strategies. The reasons for this may include staffing and resource constraints, staff turnover, and confusion arising from the HIV, Hepatitis C and related diseases model. The current structures for working together may also no longer be effective.

Effective working relationships between the Commonwealth and the States/Territories is central to making progress in responding to the HIV epidemic. Implementation of the National Strategy will not be achieved without this cooperation.

A priority for action under the next Strategy should be a full examination involving all parties of Commonwealth and State/Territory working relationships under the National HIV/AIDS Strategy. The aim here should be to identify improved processes for cooperation, coordination and implementation of the National Strategy.

Intergovernmental Committee on HIV/AIDS, Hepatitis C & Related Diseases (IGCAHRD)

IGCAHRD has been an important vehicle for exchanging information, coordination and developing Commonwealth and State/Territory plans for implementing the National Strategy.

However, in recent years IGCAHRD has lost momentum. In 2001 there were discussions about possibly winding up the committee. Currently, there is more enthusiasm for revitalising IGCAHRD among some stakeholders. This is welcome, because some kind of regular formal mechanism for the States/Territories and the Commonwealth to discuss and review implementation of the National Strategy is essential.

The Commonwealth and States/Territories should examine the operation of IGCAHRD and make any necessary changes to roles, responsibilities and operation. A model needs to be devised that allows formal interaction between Commonwealth and State/Territory departmental representatives and input from key stakeholders such as the community sector.

Recommendation:

That a full examination be undertaken by all parties of Commonwealth and State/Territory working relationships under the National HIV/AIDS Strategy. The aim should be to identify improved processes for cooperation, coordination and implementation of the National Strategy.

3.5 Community Based Response

The community sector is a vital player in the Australian HIV response. Education and prevention services to populations at high risk are provided almost exclusively through community based AIDS Councils, injecting drug user groups, sex worker groups and people with HIV/AIDS organisations. Community based programs continue to be a key element in provision of care and support for people with HIV/AIDS. The community sector also plays a pivotal role in the development of Australia's policy response to HIV.

A key principle in the 4th Strategy is that the community sector must be centrally involved “*at every level of the response – in the planning, delivery and evaluation of HIV programs, services and policies.*” However, to give full meaning to this principle the community sector must be properly resourced. During the life of the 4th Strategy the environment has become more challenging and the issues in HIV treatment, care and prevention more complex. At the same time, funding and resourcing for community-based organisations has not kept pace with these demands in real terms.

Some of the issues that have emerged for the community sector creating a more difficult operating environment are:

- *Attracting and keeping a skilled workforce.*

In the early years the workforce of the community response was characterised by a peer-based model with committed members of affected communities working in both paid and voluntary capacities. While this continues to a substantial extent, over the last 15 years there has necessarily been movement to a more professionalised, skilled staffing model, reflecting added complexity in treatment, care and support services and policy development. However, attracting and keeping a skilled workforce is difficult for community-based organisations due to limited capacity to financially reward staff. Changes to Fringe Benefits Taxation legislation introduced in 2001 added to this difficulty.

“Burnout” of staff is another issue faced by community-based organisations. This was particularly problematic during the early 1990s when the number of people dying from HIV was at its highest. However, even in the current environment, the intense demands of working in the community HIV response, combined with comparatively low financial rewards, means that community based organisations regularly lose skilled staff and along with them corporate knowledge and history of the epidemic.

- *Maintaining a volunteer workforce*

Attracting volunteers is becoming more difficult as perceptions that HIV is “less of threat” have grown within affected communities and the wider community. The activities conducted by community-based organisations depend significantly on a large volunteer workforce. As attracting volunteers becomes more difficult, the ability of organisations to provide the same level of services is restricted.

- *Skills Building around policies, program and strategies to respond to a difficult environment*

A key role for AFAO and other peak community organisations is to build skills within their members to enhance their response to current complexities in HIV. This is achieved through workshops and other skills building initiatives. Funding from the Commonwealth Department of Health and Aging for skills building activities significantly assists this and must continue. While funding and infrastructure for HIV workforce training and skills development is supported by some State Health Departments, such as in NSW, a greater level of overall support is needed at State/Territory level.

- *Disengagement of gay communities.*

Several factors have led to a general perception among the gay community that HIV/AIDS has become less of a health threat.

The advent of antiretroviral treatment, particularly, has meant that deaths have declined and a significant proportion of people with HIV are living longer. The visible presence of HIV marked by a high death and morbidity rate within the community that was a feature of the 1980's and early 1990's has now changed. Optimism about the effectiveness of treatments, leading to a belief among numbers of gay men that HIV is a chronic, manageable and treatable illness. Added to this optimism is a sense of fatigue among many of those gay men who have experienced a decade characterised by fear and death and now wish to move on from that experience. Disengagement of the gay community over recent years provides considerable challenges to community based organisations in providing HIV education and related health promotion.

- *Static funding and rising costs.*

Funding to community based HIV/AIDS organisations has generally remained static over the life of the 4th Strategy – a trend which began some years earlier. In some instances funding has decreased. Combined with rising operational costs this has placed organisations under considerable pressure to achieve the same level of output. In some cases organisations have had to reduce staff and/or the level of resources and services.

- *Budget constraints affecting the delivery of care, support and prevention services.*

A number of community based organisations have had to face unacceptably difficult choices in the delivery of care, support and prevention services. The Victorian AIDS Council is a case in point. Rising staffing and operational costs over many years, which were not matched by increased funding, resulted in significant reductions in program budgets. This meant education campaigns and resources to address local needs were unable to be done (this has only been partially addressed following alarm created by rises in HIV infections in Victoria in 2000 and 2001). Other community based HIV organisations are experiencing similar financial problems.

A contributing factor has been the failure of the 3^d and 4th Strategies to address problems in accountability and monitoring. This in turn has led to the Commonwealth and the States/Territories themselves being unable to determine clear, detailed benchmarks and standards for the delivery of prevention, care, support and treatment. Without such agreed benchmarks and standards, it is difficult for community based organisations to advocate for appropriate funding increases either to keep pace with rising costs or to undertake new programs and activities in response to emerging challenges. The situation regarding levels of prevention education and information to homosexually active men referred to extensively in this submission illustrates this difficulty.

- *Lack of funding for key parts of the community sector.*

AFAO welcomes the provision of Government Community Sector Support Scheme funding to NAPWA and other project funding for AIVL during the current strategy. This funding has enabled these organisations to establish basic secretariat and policy infrastructure. Additional funding is needed to enhance the role of these key organisations in the national HIV response.

AFAO is very concerned that the national sex worker organisation, Scarlet Alliance, remains unfunded. The 4th Strategy names sex workers as a priority group and lists as a challenge the need to “*expand sex worker organisations’ capacity to design, manage and participate in peer-based health promotion activities and to participate in the broader partnership response to the epidemic*”.

AFAO provides a small amount of funding (\$30,000 pa) to assist Scarlet Alliance with communication amongst its members. However, the ability of Scarlet Alliance to properly represent and advocate on behalf of sex workers and participate in the response in a meaningful way is not possible without adequate Government financial support.

Recommendations:

That IGCAHRD and AFAO, in consultation with other relevant community based organisations, review funding levels for community based organisations in light of new challenges and difficulties in responding to HIV/AIDS outlined in this submission.

That this process be informed by the development of clear benchmarks and standards for delivery of prevention, education, treatment, care and support services, as well as policy development and advocacy work that is also a key role of a large number of community based HIV organisations.

That adequate funding be provided to Scarlet Alliance to allow full participation in the HIV response.

3.6 PROGRAM, ACTIVITY & FUNDING ACCOUNTABILITY

Introduction

Detailed information on HIV funding levels and specific activities and programs being undertaken with these funds is central to an effective HIV/AIDS response. This information is needed to:

- review priorities.
- assess if benchmarks and standards are being met.
- monitor and evaluate Australia’s HIV/AIDS response.
- respond promptly to a change in the epidemic or serious emerging issue.

The 4th Strategy sets out five objectives in the Monitoring and Evaluation chapter. These are:

1. *Contribute to improved health outcomes by measuring the Strategy’s performance with reference to its stated purpose and priorities, at both the national and the State and Territory levels, with particular reference to the Strategy’s efficacy and cost-effectiveness in terms of health outputs and outcomes.*
2. *Provide a mechanism for securing the accountability of all levels of government and other people.*
3. *Provide a means of communicating to the wider community the successes of the Strategy and the challenges that need to be met.*

4. *Ensure that the Strategy's objectives and priorities are continually informed by the best available social and epidemiological evidence.*
5. *Meet program managers' and policy makers' need for timely, accurate information on program performance, especially in the context of Commonwealth and State and Territory planning and program management.*

Only one of the above objectives has been met – providing social and epidemiological evidence to inform the implementation of the strategy.

Failed Monitoring, Accountability & Evaluation Mechanisms

The 4th Strategy, like its predecessor, has failed to provide performance monitoring and accountability mechanisms to provide a detailed picture of HIV/AIDS programs and activities being undertaken at Commonwealth, State/Territory, community and local levels.

The genesis of this accountability problem is changed funding arrangements between the Commonwealth and the States/Territories implemented in 1996/97. This resulted in a devolving of detailed planning and policy for all aspects of HIV related health service delivery from the Commonwealth to the States/Territories. Dedicated Commonwealth funding programs like the matched AIDS Funding Program were replaced for all aspects of HIV/AIDS service delivery by the Public Health Outcome Funding Agreements (PHOFAs) and the Australian Healthcare Agreements for Medicare (except for the special funding for the National Indigenous Australians Sexual Health Strategy).

The HIV/AIDS project register operated by the Commonwealth was also wound up. The Commonwealth, State/Territory and the community based sector all contributed to this register. While not perfect, this instrument did provide a considerable amount of information on how HIV funding was being spent and on what activities.

The absence of HIV funding and activity information is not only a problem at Commonwealth and State/Territory level. It is also a problem at local level in the States/Territories. Various States/Territories have devolved funding and program responsibility for HIV from health department to local health board or health service level. Accurate information about HIV programs and activities at these local levels is minimal to non-existent.

Public Health Outcome Funding Agreements (PHOFAs)

The review of the 3^d Strategy noted that the community sector and State/Territory Health Departments had expressed concerns flowing from the broad-banding of HIV/AIDS funding. In particular, the community sector was concerned that the performance indicators under the Public Health Outcome Funding Agreements (PHOFAs) were the single most important way of ensuring that funding decisions at State and Territory levels are consistent with national goals.⁵

While the performance indicators under the second round of PHOFAs are marginally better than those in the first round - which were widely criticised by all sectors of the HIV/AIDS response - they remain completely inadequate for assessing the extent to which the objectives of the National HIV/AIDS Strategy are being delivered.

⁵ Australian National Council on AIDS and Related Diseases, *Proving Partnership: Review of the National HIV/AIDS Strategy 1996-97 to 1998-99*, Commonwealth of Australia, 1999, pp117-119.

The PHOFA indicators also do not cover:

- treatment, care and support services, some of which are funded under the Australian Healthcare Agreement;
- the extent to which there is an enabling legislative and policy environment;
- HIV related research, which is funded under a different mechanism; or
- international assistance and cooperation, which is funded under a different mechanism.

Even if the performance indicators were substantially more robust, there is currently no transparent mechanism in place where the outcomes under the PHOFAs are reviewed and examined to identify any gaps in services or any areas where the objectives identified in the Strategy require more funding or attention.

The decision to make the PHOFAs and the State/Territory Reports of Outcomes available on the Australian Department of Health and Ageing website is welcomed by the community sector as an aid to transparency. However, an examination of the reports on the first year of the current PHOFAs reveals a diversity of ways in which the outcomes are reported and it is almost impossible to relate the reports to the National Strategy objectives. Although the PHOFAs contain many common performance indicators for HIV/AIDS, the wide disparity in the ways in which the States/Territories are reporting does not provide timely, accurate information on program performance which can be used at a national level.

HIV Prevention & related Health Promotion for Homosexually Active Men – A Case Study

In section 4.1 (HIV Related Health Promotion) AFAO discusses the increased vulnerability to new HIV infections among homosexually active men. This population is listed as the highest priority for HIV related health promotion efforts under the 4th Strategy.

Funding for prevention programs and activities targeting homosexually active men is now believed to have fallen to a very low percentage of Australia's overall HIV funding – in some jurisdictions as low as 10% to 15%. Yet homosexually active men comprise 80% of the Australian HIV caseload and are the large majority of new HIV infections.

Current prevention activities and related funding needs to be re-assessed by all States/Territories and the Commonwealth. Detailed benchmarks should be established for the delivery of HIV prevention and related health promotion information targeting homosexually active men – in urban, outer urban, regional and rural areas. These benchmarks need to be turned into actual programs and activities.

However, the starting point for such action is access to detailed information about the programs, activities and funding that is already in place. This information is not available and the Commonwealth and State/Territories have been unwilling to take action to obtain it. Therefore Australia's overall response to the threat of new HIV infections among homosexually active men remains piecemeal, uncoordinated and dangerously deficient.

Attempted Reform of Monitoring, Accountability & Evaluation Mechanisms

Various attempts have been made to address the national problem in monitoring, accountability and evaluation. None have proven successful.

Through 2001/2, the issue was discussed at length by the ANCAHRD HIV Committee. The Committee recommended –

“That the Commonwealth lead a cooperative effort to devise new mechanisms aimed at ensuring that comprehensive information is obtainable on HIV/AIDS programs and activities and related funding being delivered at Commonwealth, State/Territory, community and local levels.”

This recommendation is yet to be acted on.

On the subject of prevention efforts targeting homosexually active men, the ANCAHRD HIV Committee recommended –

“That the Commonwealth seek the cooperation of State/Territory, community and local levels to undertake a review of HIV prevention programs, activities and related funding targeting homosexually active men.”

Attempts to implement this recommendation were hampered by unhelpful actions by the main ANCAHRD committee and apparent lack of will by the Commonwealth and the States/Territories. During 2002 there have been discussions between the HIV Committee and the IGCAHRD on the above recommendation. To progress the issue the HIV Committee has proposed a set of questions (see Appendix B) for States/Territories to the IGCAHRD aimed at gathering information on HIV prevention and related health promotion programs, activities and funding targeting homosexually active men. Negotiations on these questions have reached gridlock.

It is a matter of considerable regret that the 4th Strategy Review does not a comprehensive picture of HIV programs, activities and related funding to inform its deliberations.

Future Monitoring, Accountability & Evaluation Mechanisms

Given the experience of the first two sets of PHOFAs, it appears most unlikely that the HIV performance indicators in the PHOFAs will ever provide a complete set of indicators for assessing whether the outcomes of the National HIV Strategy are being delivered at a Commonwealth and State/Territory level.

The monitoring and evaluation of the Strategy requires a set of performance mechanisms and indicators that:

- address the relationships between the Commonwealth and States and Territories in a transparent way;
- provide measurable outcomes for community and government, linked to the objectives in the Strategy;
- provide for diverse responses that take account of differences in the epidemic in each State and Territory; and
- allow the development of innovation and capacities for flexible local responses.

New performance mechanisms indicators also need to monitor how and the extent to which the objectives in the Strategy are being implemented, to provide for greater scrutiny by all members

of the partnership of the way funding is allocated and expended, and to identify any gaps in services which need to be addressed. All members of the partnership should be involved in developing these improved mechanisms and performance indicators.

It is clear from the experience of the past six years that the PHOFAs and other broad-banding mechanisms are not suitable to provide the program, activity and funding accountability information needed for Australia's continuing HIV response.

The best solution appears to be a return to the Commonwealth Matched Funding Program for HIV/AIDS with the States/Territories – or at least a form of matched funding to cover HIV prevention and related health promotion. While most health related matched funding programs have been wound up, there are a number which remain in place due to the special nature of the problem - HIV/AIDS should be treated similarly.

Recommendations:

That all members of the partnership be involved in developing new mechanisms for HIV funding, accountability, monitoring and evaluation. These should be identified and established by 1 January 2003.

That a Commonwealth and States/Territories Matched Funding Program for HIV/AIDS be reintroduced – in particular to cover HIV prevention and related health promotion.

That the recommendations of the ANCAHRD HIV Committee relating to mapping HIV related health promotion programs, initiatives and funding targeting homosexually active men be actioned by 1 November 2002, and that establishing related benchmarks be completed by 1 January 2003.

PART IV: ASSESSMENT OF KEY AREAS OF THE NATIONAL STRATEGY

4.1 HIV Prevention & related Health Promotion

4.1.1 Homosexually active men

◆ *Priorities vs Realities*

The 4th Strategy places homosexually active men as the highest priority in maintaining a successful HIV/AIDS response in Australia as they are identified as the most vulnerable to HIV transmission (comprising 85 % of infections).

AFAO believes this priority is not being reflected in terms of resource allocation or leadership focus in most jurisdictions.

The 4th Strategy also states that a challenge for HIV prevention and related health promotion to homosexually active men is to “*improve the dissemination of health promotion messages, through a range of services, for target populations*”. This challenge is not being met either.

Poor levels of accountability and transparency in tracking spending and activities make it difficult to gauge the precise extent of the effective down-grading of HIV prevention and related health promotion targeting homosexually active men.

◆ *Socio-Sexual Context Requires Sophisticated Education Programs*

This lack of accountability is a dangerous development as the socio-sexual context which has developed over the last five years requires more sophisticated HIV prevention and related health promotion programs. These are necessary because:

- increases in unprotected anal intercourse with both casual and regular partners are reported in many Australian cities (and in comparable cities overseas).
- many gay men are adopting quite sophisticated though highly variable risk reduction strategies.
- a series of outbreaks of sexually transmitted infections has occurred in most cities.
- more effective treatments has lead to more homosexually-active men living with HIV than ever before.
- treatment protocols have shifted to deferred treatment, ‘treatment breaks’, and changing management goals which is likely to lead to increased numbers of PLWHA with higher viral load, making some of the risk reduction strategies which are being employed more hazardous.
- several generations of gay men now have quite varying experiences of the epidemic ranging from those exhausted by it to many not having been through the personal experience of knowing someone who has died.
- demographic diversity and cross-cultural communication issues have increased.
- notions of gay identity and community attachment have changed.

- there are degrees of community ‘disengagement’ from HIV.
- the Internet is impacting on sexual cultures and sexual contexts.
- there are changes in recreational drug use among gay men.
- PEP (Post-Exposure Prophylaxis) is becoming available in major cities.
- there is a developing “behavioural sophistication” which has led to a diversification of harm reduction strategies based on knowledge of and capacity to utilise clinical markers (usually viral load).
- some research is suggesting gay men are testing for HIV less frequently.

The changing context of HIV in gay communities will continue to present new challenges to HIV community organisations and HIV educators. The emergence of quite complex risk reduction strategies by gay men, such as strategic positioning (the adoption of insertive or receptive roles for unprotected anal sex based on HIV status to reduce the risk of HIV transmission), withdrawal (pulling out before ejaculating) and partner selection based on sero-status is a major challenge faced by educators - requiring both careful research and innovative program design and delivery.

This set of circumstances has made HIV transmission prevention education more complex than any other health promotion program in Australia.

◆ *HIV Testing Rates*

There is some evidence to suggest that, while the number of gay men who have had a HIV test remains constant, the frequency with which gay men are testing for HIV has declined over the last five years⁶. This requires further research and investigation. Regardless of what is occurring with testing patterns, knowledge of individual HIV status is an important aspect in HIV prevention. Promotion of HIV testing needs to be expanded and should occur in the context of broader STI testing. Such promotion needs to occur as a coordinated effort between community-based educators, State and Territory health departments, sexual health clinicians and general practitioners.

Nationally consistent guidelines for STI and HIV testing for gay men need to be developed which provide guidance for frequency of testing based on individual sexual behaviour. For example, men who are regularly sexually active may need to test more frequently than others.

◆ *Inadequate Levels of HIV Prevention & related Health Promotion*

AFAO acknowledges there is support for innovative and sexually explicit education resources at the Commonwealth level and at most State/Territory levels. We also acknowledge that the methods of health promotion employed by the community sector and the challenging education issues we face are understood and supported by Government in most instances. We commend this essential support as a demonstration of effective partnership.

However in most jurisdictions this support is not backed up with sufficient resources to properly deal with the complexities associated with providing HIV prevention and health promotion to homosexually active men in a challenging environment. In fact, since the mid 1990s there has been a decline in funding in real terms in most areas.

⁶ P van de Ven, P Rawstorne, J Crawford, S Kippax, Facts and Figures 2000 Male Out Survey, NSHSR, 2001

The absence of any effective mechanisms to track HIV funding allocations through the Public Health Outcomes Funding Arrangements (PHOFAs) is a key reason for these difficulties. This has impacted on the ability of partners within the Strategy to adequately address the real needs of this priority group. The devolution of program delivery responsibility to the States/Territories under the PHOFAs has made a nationally consistent approach to prevention and health promotion more difficult.

We have addressed these issues in detail in section 3.6, *Program, Activity and Funding Accountability*, and made recommendations designed to improve the situation. Given the challenges facing Australia's HIV response, it is imperative that action be taken urgently to ensure that programs, activities and funding for HIV prevention and related health promotion targeting homosexually active men is commensurate with the highest priority accorded this group under the 4th National HIV/AIDS Strategy.

◆ *Leadership on Key Challenges*

The advent of the PHOFAs has also seen a downgrading in Commonwealth leadership, resulting in a winding back of dedicated funds to address priorities in the area of homosexually active men. Three key examples are:

- *Implementation of a dedicated national campaign on the availability of non-occupational post-exposure prophylaxis (PEP) targeting homosexually active men:* While some States/Territories have clear non-occupational PEP policies, others have none or are yet to effectively implement them. Similarly, resourcing and impetus to advertise PEP's availability is inconsistent. National implementation of non-occupational PEP policies and benchmarks for its delivery are required.
- *Targeting non gay identifying homosexually active men through rural outreach projects, comprehensive 'beats' programs & venue outreach programs:* These programs are sporadic and action is needed to address this.
- *Implementation by IGCAHRD of the 'Infrastructure Benchmarks for HIV Education for Gay & Homosexually Active Men Report':* This report has not been endorsed because some States are concerned about cost implications. Failure to endorse this report is an example of the way in which the national response has been undermined by the devolution of program and funding decisions. Adoption of the Benchmark Report needs to be followed by work to identify and agree on baseline standards (ie. specific activities and programs to be carried out) for the delivery of HIV prevention and related health promotion to homosexually active men in urban, outer urban, regional and rural areas of Australia.

Recommendations:

That action be taken to ensure that programs, activities and funding for HIV prevention and related health promotion targeting homosexually active men is commensurate with the highest priority accorded this group under the 4th National HIV/AIDS Strategy (refer also to recommendations in section 3.6, "Program, Activity and Funding Accountability").

That homosexually active men continue to be the highest priority for HIV prevention and related health promotion efforts under the 5th National HIV/AIDS Strategy.

That States and Territories immediately collaborate to ensure nationally consistent policies regarding the availability of non-occupational Post Exposure Prophylaxis (PEP), as well as consistent implementation of such policies. Implementation should also include financial support for the promotion of PEP to at risk communities.

That the Guidelines for Infrastructure Benchmarks for HIV Education for Gay and Homosexually Active Men be endorsed by IGCARD and that detailed benchmarks for the delivery of prevention and health promotion activities be developed and implemented by all States and Territories.

4.1.2 People who inject drugs

◆ Current challenges

Australia has retained very low HIV transmissions through injecting drug use through –

- an extensive, multi-faceted and highly innovative Needle Syringe Program (NSP).
- the involvement of peers through State and Territory drug user organisations, peer education programs for injecting drug users and the work of the Australian Injecting and Illicit Drug Users League (AIVL).

The outstanding success of this part of the HIV/AIDS Strategy is now under significant challenge on several fronts. Concerted action will be required in the short-term to ensure Australia does not suffer an upsurge of infections among injecting drug users similar to those experienced in many comparable countries.

AFAO notes these challenges arise from:

- diverging emphases and interpretations of the principles of harm reduction between the National HIV/AIDS and Hepatitis C Strategies on the one hand, and the National Illicit Drugs Strategy on the other;
- public liability insurance premium increases effectively forcing closure of the non-government NSP sector;
- Waning public and political support for NSPs;
- inadequate funding for State and Territory drug user organisations and peer education programs given their expanded responsibilities for Hepatitis C in addition to HIV;
- restricted access to treatment, counselling and support services; and
- the proposed trial of Retractable Syringes.

◆ Harm Reduction principles

The Commonwealth government's increased emphasis on 'drug prevention' over the last several years is reducing commitment to the principles of harm reduction incorporated in the HIV/AIDS and Hepatitis C Strategies. This subtle shift over time is creating a more difficult environment for NSP outlets and drug user organisations to operate effectively. For example, some local law enforcement authorities have closed or threatened to close NSPs or have used the environment to threaten closure of other agencies which participate in harm reduction practices, such as fits disposal bins in brothels.

While AFAO welcomes the stated position and recommendations taken by Australian National Council on Drugs in its *Position Paper on Needle & Syringe Programs [2002]*, we nonetheless believe the overall policy framework in which NSPs are now operating is under-mining harm reduction principles and practice.

AFAO notes the 4th Strategy gave ANCAHRD a role “*in monitoring consistency in the application of harm minimisation strategies and in recommending remedial action should this be required.*” AFAO believes that remedial action is now required.

Of concern are increasing attempts to “rename” harm reduction. Harm reduction is a widely accepted term, both in UNAIDS and WHO. In the IDU area, it encompasses not only strategies to reduce harm to users, including potential transmission of blood borne viruses, through a range of direct programs and services (like NSP, treatment and care, support, counselling, etc), but also the creation of an environment to give every opportunity for harm reduction to work. This enabling environment covers a wide range of areas, from services and programs that are sensitive to drug users mentioned previously, through to policies and laws which enhance a harm reduction approach. Recently we have seen attempts in Australia to change “harm reduction” to “risk reduction” and even to “prevention of risk and harm”. These terms actually undermine the concept of “harm reduction” in its fullest (and necessary) meaning. These terms convey different and more limited meanings and have the potential to undermine the true concept of “harm reduction”.”

Recommendation:

That the HIV Committee and HCV Committee jointly develop a position paper advising the Minister on the erosion of harm reduction principles involving injecting drug use and their concerns regarding the impact on public health outcomes. This paper should include specific actions to be undertaken by the Commonwealth and States and Territories, and should be completed by the end of 2002.

◆ *Public liability insurance premiums and non-government Needle Syringe Program (NSP) outlets*

Insurance companies appear to be routinely increasing public liability insurance premiums such that a number of non-government NSPs have already closed and many others are unlikely to be able to afford to renew when their current policy expires.

The increases in premiums bear no relation to any actual risks involved in NSP outlets and are routinely several orders of magnitude higher again than those experienced by sporting clubs, where risk of physical injury is inherent to the activities of the organisation. The level of risk is minimal in the case for NSP outlets.

AFAO believes premiums are being increased on prejudicial grounds. There do not appear to be any actuarial grounds for these increases: our colleagues at AIVL have not been able to identify a single case of a claim against any non-government NSP.

NSPs which have *already* closed include:

- CAHMA – formerly the second largest NSP outlet in Canberra.
- DUNES – the only NSP outlet operating at the northern end of the Surfers Paradise conurbation.

- NUAA – a significant NSP outlet in central Sydney.

Several State governments have arranged temporary coverage (e.g., Western Australia) but this is not likely to be open-ended.

The effective removal of non-government NSPs significantly reduces choice for injectors and is particularly problematic for those users who prefer not to interact with government agencies (e.g., those who may be breaching parole by injecting). It also reduces the critical opportunities for peer-based interactions to take place, significantly jeopardising the whole peer education program.

Recommendation:

The HIV Committee and HCV Committee advise the Minister of the likely impact on public health of the effective obliteration of the non-government Needle Syringe Program outlets and urge a resolution to be sought within the overall negotiations taking place between the government and the insurance industry; and, that the Minister raise this issue with the Australian Health Minister's Council with the view to seeking a resolution.

◆ *Funding for Peer education programs for people who inject drugs*

Drug user organisations have been required to substantially widen their education programs over the last several years. This has arisen primarily from realisation of the likely extent and nature of hepatitis C transmission moving from an estimated 11,000 new transmissions in 1996 to an estimated 16,000 new transmission in 2001⁷.

Most of these infections are occurring among young injecting drug users - requiring a significant expansion of peer education programs if further impact on the hepatitis C epidemic is to be made.

User organisation education programs have also had to be widened to provide advice and information about the wider range of drugs now being injected, partly as a result of the 'heroin drought' over the last two years.

AFAO notes with concern that the peak body, the Australian Injecting and Illicit Drug Users League (AIVL) receives no funding from the HIV funding stream of the Department of Health and Ageing. This in effect eliminates AIVL's focus and capacity to develop and deliver HIV/AIDS policy and programs. Given the on-going potential for an HIV epidemic among drug users this situation should be rectified.

Recommendation:

That resources for drug user organisations and peer education programs for injecting drug users be reviewed to ensure they have sufficient capacity to combat transmission of both HCV and HIV.

◆ *Proposed Trial of Retractable Syringes*

⁷ *Estimates and projections of the hepatitis C epidemic in Australia 2002. ANCAHRD Hepatitis C Virus Projections Working Group, May 2002, p.28*

The Commonwealth government has allocated funds for a trial of proposed retractable syringes. AFAO believes this trial should not proceed on three grounds:

- Public health outcomes which will increase infections of HCV and HIV.
- financial analysis which indicates the trial is a waste of money and therefore a mis-allocation of resources.
- the stated public health outcome of the trial has no evidence base to justify allocating any resources to it.

Introduction of retractable syringes universally is likely to result in increased sharing of injecting equipment leading to increased HCV and HIV transmission, because:

- Instances will inevitably arise at least occasionally where only one needle is available.
- Retractable models to date have been able to be re-assembled relatively easily but their re-assembly prevents effective cleaning between injecting episodes.
- Problems encountered in an injecting episode will likely lead to assistance by others, as blood will already be involved this will increase opportunities for HCV transmission.
- Many users will prefer current technology, leading to widespread re-using of equipment and increased vein-care problems from blunt needles.
- As per unit costs are likely to be substantially more expensive the State/Territory governments are unlikely to increase NSP budget allocations by this amount, leading to a substantial reduction in the availability of injecting equipment, compounding the problems outlined above.

In financial terms the introduction on retractable needles is highly unlikely to be effective because:

- the increased costs is likely to lead to some or all State/Territory governments retaining current technology for NSPs.
- the other major market, people with diabetes, would see no benefit in retractables and avoid a more expensive product.
- the public and private hospital sector are unlikely to see any benefit and would most likely retain current technology on cost grounds.

AFAO believes the stated public health benefit of retractable needles - preventing infections from inappropriately discarded injecting equipment – has no evidence-base. We are unaware of even one documented case of transmission of any infection through discarded injecting equipment. On the other hand, there is an overwhelming evidence-base for the need to combat effectively the rapidly expanding Hepatitis C epidemic in Australia, and to sustain success in minimising transmission of HIV.

Recommendation:

That the proposed trial of retractable syringes not be proceeded with.

◆ *Treatment, counseling and support services for injecting drug users.*

Concomitant with harm reduction approaches to minimise transmission of blood borne viruses through injecting are strategies to reduce the number of people actually injecting drugs. This is

best achieved through providing effective access to treatment, counselling and support services which are sensitive to the needs of IDU.

Treatment availability for illicit drug users remains a significant problem throughout Australia. Treatment for opiate dependency is characterised by long waiting lists or by refusal to even have a waiting list because the demand is so high. Within States/Territories, treatment availability varies enormously depending on geographical location and other factors. Co-payment and other costs of treatment is a serious issue for illicit drug users who want to undertake treatment – significant numbers of people cannot afford such treatment and this is a barrier both to uptake and to successful ongoing treatment.

Recommendation:

That the Hepatitis C and HIV Committees examine the efficacy of current treatment and support programs for illicit drug users, especially as they relate to blood borne viruses, and develop a plan to address this by 1 June 2003.

4.1.3 Education for People with HIV

During the life of the 4th Strategy one of the biggest challenges has been the ability of education and health promotion initiatives to meet the demands of both positive education and prevention education.

There has been little extra resourcing for this area and little recognition from Government that the needs in both these areas are becoming increasingly complex.

HIV education is increasingly expected to undertake an expanded range of activities to incorporate health promotion for an increasing number of HIV positive constituents. The challenge of providing detailed inter-sectoral information – welfare, health, legal issues – has increased pressure on a shrinking education health budget which is continuing to address HIV prevention within a broader sexual health agenda.

Positive education needs to keep a focus of wellness within a broader health maintenance framework. Issues such as family, employment and returning to work as well as community, disclosure and discrimination need to be addressed. Positive education is often relied on to support and underpin HIV prevention education based messages. HIV positive people more generally also need access to information about HIV prevention based strategies.

A strength of the community based response is understanding the changing needs of PLWHA as they emerge and being able to respond in appropriate and focussed ways. However, timely responses require flexible funding arrangements so that outputs and outcomes can be negotiated when needed.

Recommendations:

That program resourcing be reviewed to ensure they are sufficient to meet the increasingly complex demands of providing HIV education and related health promotion for people living with HIV/AIDS.

Recommendation

That funding arrangements for community based organisations include flexibility to renegotiate outputs and outcomes to allow for timely responses to changing needs.

4.1.4 Sex Workers

HIV infections remain low among Australian sex workers, demonstrating the effectiveness of peer-based initiatives. However, the situation remains volatile given the series of legislative changes in various jurisdictions, many of which threaten, rather than promote, safe environments for sex work (for a more detailed discussion of these changes see section 4.6. 'An Enabling environment' of this submission).

AFAO would welcome the funding of a national training program for sex work educators, similar to the successful model that has been completed for educators of gay and homosexually active men.

The 4th Strategy lists as a challenge the need to “*expand sex worker organisations’ capacity to design, manage and participate in peer-based health promotion activities and to participate in the broader partnership response to the epidemic*” (p. 20). This challenge remains unmet. A further barrier to meeting this challenge is that the national sex worker organisation, Scarlet Alliance, remains unfunded. Core funding should be provided for Scarlet Alliance to ensure full participation of sex workers in the HIV response.

Recommendation:

That core secretariat funding is provided to the Scarlet Alliance to ensure that national policy development and co-ordination incorporates all members of the Partnership.

4.1.5 People in custodial settings

As noted in the 4th Strategy –

“The high levels of needle sharing, the continuing availability of drugs, and the mixing effect resulting from the high number of internal transfers of inmates within and between institutions increase the risk of an outbreak of HIV among people in correctional facilities. From the national perspective, prevention, education, and reducing the extent of unsafe sexual and injecting behaviours should be central to efforts designed to curb the spread of HIV in these facilities.” (p.19)

The 4th Strategy calls for enhancing prevention and other programs in custodial settings directed at both inmates and staff. Progress in this area has been minimal. This underlines the ongoing need for a whole-of-government response to HIV, including at the State/Territory level. Greater efforts are needed through Commonwealth leadership with State/Territory jurisdictions to improve and expand prevention and other programs in custodial settings.

4.1.6 Mobility & Migration Issues & HIV/AIDS

This is an issue that requires additional action. Some work in mapping the issues around HIV and mobility and migration has been started by the HIV Committee. The objective was to inform to a

workshop to develop strategies on mobility, migration and HIV.. This matter should be given a high priority in the 5th Strategy.

Recommendation:

That issues relating to mobility and migration receive high priority for attention and planning.

4.2. Aboriginal and Torres Strait Islander People

The Epidemiological Context

To date, overall reported rates of HIV and AIDS diagnoses *per capita* have differed little between Indigenous and non-Indigenous people. In both populations, the most frequently reported route of transmission is male homosexual contact. However a higher proportion of heterosexually acquired cases of HIV infection has been reported among Indigenous people (36 %) compared with non-Indigenous people (16 %) ⁸.

However, our knowledge of the nature and extent of the HIV epidemic among Indigenous Australians is not underpinned by reliable epidemiological data to the extent that it is for other affected communities. For Indigenous Australians, statistics are more limited because:

- HIV epidemiological data has only included information about Aboriginality since 1993 (compared with a starting date of 1984 for Australian HIV epidemiological data overall);
- reporting of Aboriginality is by self-report, leading to under-reporting; and
- confidentiality concerns are often more intense in Indigenous communities, contributing further to under-reporting.

It is possible there is a wider epidemic in Indigenous communities than is currently documented by epidemiological data – although increased rates of HIV testing in sentinel populations of Indigenous people recently make a significant “hidden epidemic” unlikely. However, the nascent epidemic could rapidly expand in Indigenous communities because of:

- high rates of non-HIV sexually transmissible infections among Indigenous people in the Northern Territory, South Australia, Western Australia and Queensland. (The interpretation of data from other States and Territories is limited by incomplete information on Indigenous status).
- a reported rapid increase in rates of injecting drug use. National surveillance data released in May 2002 on Indigenous status and injecting drug use indicates increasing HIV infections among Indigenous people from injecting (though still in small numbers). Reports from members of AFAO’s Indigenous Project Steering Committee, from the Indigenous Project Officers’ Network and from the Australian Injecting and Illicit Drug user’s League (AIVL), strongly suggest that the practice of injecting illicit drugs is increasing rapidly in some Indigenous communities.

⁸ All epidemiological data quoted in this section comes from the National Centre in HIV Epidemiology and Clinical Research’s *Annual Surveillance Report 2001: HIV/AIDS, Viral Hepatitis and Sexually Transmissible Infections in Australia*, at p. 17.

A Complex Policy Context

The policy context for work in HIV prevention and sexual health promotion with Indigenous people is complex. National frameworks are provided by:

- the National HIV/AIDS Strategy;
- the National Indigenous Australians' Sexual Health Strategy and its implementation plan;
- the National Drug Strategy;
- Framework Agreements on Indigenous Health;
- the AFAO National Indigenous Gay and Transgender Sexual Health Strategy,
- the National Indigenous Health Strategy; and
- State/Territory HIV/AIDS strategies in some jurisdictions.

This range of policy documents and strategic frameworks causes confusion among frontline workers, organisations involved in program and service delivery and other stakeholders.

Recommendation

That the overall policy framework encompassing Indigenous HIV and sexual health issues be clarified and stream-lined during the life of a 5th National HIV Strategy.

Work of AFAO and AFAO Members under the 4th National HIV/AIDS Strategy

The 4th Strategy states that AFAO's National Indigenous Gay and Transgender Sexual Health Strategy will continue to emphasise HIV prevention and health promotion for Aboriginal and Torres Strait Islander gay men and sistersgirls.

AFAO has continued to build on its work with Indigenous gay men and sistersgirls during the 4th Strategy through its Indigenous Project. The work of the project has grown in importance and has received strong support from the Commonwealth. Three members of AFAO have also established Indigenous projects (Queensland AIDS Council, Northern Territory AIDS Council and the AIDS Council of NSW).

The AFAO Indigenous Gay Men and Sistersgirls project focuses on –

- co-ordinating development of strategies addressing key issues for the target group.
- producing a range of print resources and a training package for indigenous sexual health and HIV staff.
- conducting consultations through forums, workshops and a quadrennial Conference.
- facilitating program implementation through the national the Indigenous Project Officers Network.
- liaising with the key national indigenous health organisations.

The projects conducted by the AIDS Councils focus on program delivery in indigenous communities (within current resource constraints) including education and support work for gay men and sistersgirls and for people with HIV. In some cases it includes presentations to and engagement with wider indigenous communities on HIV and sexual health issues generally.

AFAO works co-operatively with these projects and with the National Aboriginal Controlled Community Health Organisations (NACCHO).

Inconsistent Involvement of Affected Communities

The 4th Strategy emphasises that implementation of the strategy and of the National Indigenous Australians' Sexual Health Strategy is to be addressed through the Framework Agreements on Indigenous Health, to be negotiated by State/Territory governments with the State/Territory affiliates of NACCHO, the Aboriginal and Torres Strait Islander Commission and the Commonwealth.

These agreements were established primarily as mechanisms for the delivery of Commonwealth funds to States/Territories. In some States/Territories the negotiation process has not involved affected communities, making their on-going participation as equal partners in HIV prevention and sexual health promotion at State/Territory level difficult.

In Western Australia, for example, Indigenous gay men and sistergirls were allowed only very limited involvement in negotiating the relevant agreement, and in activities carried out pursuant to the agreement. However, some experiences with these agreements has not all been negative. In Queensland, the State affiliate of NACCHO employed an Indigenous gay HIV prevention and sexual health promotion worker, and this facilitated input from Indigenous gay and sistergirl communities to the negotiation of the relevant agreement, and the agreement has provided for initiatives targeting these communities.

Health Promotion for HIV and Sexually Transmitted Infections

The Northern Territory, South Australia, Western Australia and Queensland continue to show high levels of sexually transmitted infections in Indigenous people. While sexual health services and the treatment of sexually transmitted infections have improved during the period of the 4th Strategy, there is still a need for improved monitoring and evaluation mechanisms within the Framework Agreements. These should be developed in conjunction with local Indigenous communities.

Health promotion and HIV prevention education initiatives have generally not been delivered comprehensively or satisfactorily within Indigenous communities. This task has been difficult as most indigenous communities are dealing with a wide range of severe social, economic and health-related problems, the immediacy of which displaces HIV and sexual health on the communities' agenda. The downgrading of priority for addressing HIV and sexual health issues among indigenous communities is assisted by the stigma associated with HIV.

The AFAO and AIDS Council Indigenous projects have now developed a range of strategies which have demonstrated they can put HIV and sexually transmitted infections higher on the agenda in Indigenous communities.

These projects are now sufficiently well developed to be expanded into a national program with the aim of ensuring appropriate HIV and sexual health promotion in all States/Territories. The Queensland AIDS Council project in particular has developed a successful model of engaging whole Indigenous communities in HIV and sexually transmitted infections education initiatives, as a strategy for reaching gay men and sistergirls, who are high risk members of these communities. This carefully crafted approach has been well-accepted by the Indigenous

communities in which it has been implemented, providing a vehicle for them to comprehensively address HIV and sexual health issues.

HIV and sexual health promotion has been hampered in some areas by unrealistic expectations about how much of this work can be done by HIV and sexually transmitted infections staff in Indigenous clinical and sexual health services. Heavy clinical workload and lack of training restrict the amount of health promotion work that can be delivered in practice.

Given this context it is desirable that the Commonwealth Department's Office of Aboriginal and Torres Strait Islander Health, NACCHO and the AFAO Indigenous project develop a strategy and allocate resources to refine and expand the models developed by AFAO and its Members to implement appropriate HIV and sexual health promotion programs in all indigenous communities in all States/Territories.

Recommendation:

That the Office of Aboriginal and Torres Strait Islander Health, the National Aboriginal Community Controlled Health Organisation and the AFAO Indigenous Project jointly develop a strategy and allocate resources to refine and expand the HIV and sexual health promotion models developed by AFAO and its members for implementation in all Indigenous communities in all States/Territories.

Cross-border issues

Expanding effective cross-border partnerships for preventing HIV and other sexually transmissible infections in Indigenous people is identified as a challenge in the 4th Strategy⁹.

The key areas for this work are Papua New Guinea, Torres Strait, Cape York, and East Timor - Northern Territory. A recent report for AusAID compares the potential impact of the HIV epidemic in Papua New Guinea with that of sub-Saharan Africa¹⁰, and gives some indication of the potential for epidemics in Australia's near neighbours to fuel the epidemic in Australia. This is particularly so for Indigenous Australians who have frequent cross-border contact with people from neighbouring countries.

Some work has been done with East Timor by Danila Dilba Health Service in Darwin to address HIV issues in East Timor and possible impacts on Australia. There needs to be more focus on this increasingly important work. The Implementation Plan for the Indigenous Australians Sexual Health Strategy, soon to be released, will provide a framework for further efforts.

Recommendation:

That the HIV Committee and the National Indigenous Sexual Health Committee oversee development of an overall strategy to address the potential impact on the HIV epidemic of cross-border movements along Australia's northern borders.

⁹ At p.17.

¹⁰ Report for AusAID by Dr Jenny Gordon, cited by Reuters Health, Canberra, 15 May 2002.

4.3 Treatments

HIV Treatment in Context

The availability of highly active antiretroviral treatment (HAART) in Australia in 1996 dramatically changed the way the HIV epidemic was experienced. This created a sense of optimism generated from the real improvement in health and length of life for people with long-term HIV infection.

However, the coming years are likely to be characterised by a realisation of the limitations of the existing drugs, including:

- slowly rising death rates;
- increased incidence of serious long-term toxicities associated with antiretroviral therapy;
- increased vulnerability to rises in seroconversions because of increases in community viral load due to growing rates of resistance, changes in treatments guidelines which occurred in 2000 and increasing numbers of people with HIV taking both structured and unstructured breaks from their treatments.

These outcomes can be prevented if -

- a second generation of HAART drugs becomes available (rather than more ‘me too’ drugs): However, we have not seen the development of new drugs within existing classes which are much more active, have very different resistance profiles or do not have the same serious toxicities during the last few years – this does not appear likely to change in the short to medium term.
- Completely new classes of drugs become available: While ‘virus entry inhibitors’ are looking promising, only one is likely to become available in the short term. New classes of drugs are likely to be expensive.
- Effective immunomodulators become available: While Interleukin-2 continues to hold promise for some people with HIV (but is associated with significant quality of life issues) other effective immunomodulators seem unlikely in the short to medium term.

AFAO therefore advises a cautious assessment of prospects for treatments during the next 2-4 years.

Drug approval processes and availability of new drugs

The 4th Strategy states as a challenge the need to:

“Continue to ensure the approval processes of the Therapeutic Goods Administration and related committees remain responsive to new developments in therapy, especially in relation to prompt consideration and approval of new technologies and new therapeutic agents, such as immuno-modulating agents and therapeutic vaccines.”

AFAO is concerned that approval and availability of drugs may become problematic for two reasons:

- now that there are a number of existing treatments for HIV, there is a developing tendency for HIV drug approvals to take longer.
- the suggested changes to the way drugs are assessed for listing on the Pharmaceutical Benefits Scheme (announced in the 2002 Federal Budget) may result in fewer HIV drugs being approved and/or much tighter indications for use of approved drugs may be set and enforced.

Given the increasing number of people for whom existing drugs no longer work and the impact of growing levels of drug resistance on community viral load it is essential that expedited approval to new classes of HIV drugs remain a high priority, and that indications are set at levels which allow optimum treatment.

Changes to the means and speed with which drugs are assessed may also threaten access to new treatments through the special early access programs (ie., prior to their approval and funding through the Australian health system). These programs which have been negotiated by the community with pharmaceutical manufacturers, provide possibly the best access of any country. This free access has not only saved lives and enhanced health but also saved millions of dollars for the government. However, these programs are based on an expectation by the pharmaceutical industry that new drugs will be considered promptly by the Australian drug approval and funding processes. Delays, such as we have seen recently with Kaletra, undermine the communities ability to negotiate early and expanded access to new treatments under development. Changes to the Pharmaceutical Benefits Scheme may inadvertently jeopardise this scheme, and hence timely access to new drugs. This would impact on the health and lives of people with HIV/AIDS.

Recommendation:

That the Minister for Health ensures that any proposed changes to the Pharmaceutical Benefits Scheme do not reduce or otherwise jeopardise the timely and comprehensive access Australians currently have to new HIV therapeutic agents.

Threats to the delivery of primary clinical care

High standards of care have been another success of Australia's HIV response – and have continued under the 4th Strategy.

However, two issues potentially threatening the delivery of treatments and care through primary clinical care, reducing overall standards of care. They are:

- Ramifications of moving HIV research into the National Health & Medical Research Council (NHMRC) funding structure.
- Maintaining financial viability of the HIV-caseload General Practices.

The suggested “mainstreaming” of HIV research into the NHMRC would impact detrimentally not only on Australia's HIV research program, but also disrupt our systemic provision of clinical care.

The particular trials model the NCHECR has fostered, focussing on primary care clinics (rather than just on infectious disease specialists or genito-urinary specialists, as in the USA and UK

respectively), has effectively supported continuing care for most people with HIV at local clinical practices. This clinical trials network encourages and supports general practitioners to be involved in HIV related research. Participation enhances and maintains standards of care, with direct benefit to patient outcomes. The NHMRC would be very unlikely to fund this network; thus this very successful – and extremely cost-effective – system of linking research and clinical care would be jeopardised by any move of the NCHECR into NHMRC funding mechanisms.

Appropriate remuneration of general practitioners working in HIV is another problem that must be addressed. The Medicare and Practice Incentives Program do not encourage general practitioners to spend the necessary time with HIV-positive patients. Those who do are in effect financially penalised, in some cases threatening the financial viability of their practices.

The other income source for general practitioners is from pharmaceutical companies funding participation in clinical trials and this has a number of emerging and as yet unaddressed policy questions that are broader than HIV. The increasing complexity of HIV treatments demands much more from HIV general practitioners in terms of skills and ongoing training. Failure to address this ongoing issue will eventually result in a shortage of skilled HIV general practitioners.

The confluence of these two factors is likely to jeopardise the intricate but highly effective system – effective in both appropriate care for patients and cost to government.

Recommendation:

That the Department of Health & Ageing commission a study on primary care delivery to clarify the challenges to Australia's primary HIV care system and recommend adjustments to ensure standards of care are maintained.

Treatments expertise in the community-sector

Partnership has been a cornerstone of the treatments research effort in Australia. The increasing complexity of treatments has resulted in more subject-based NCHECR subcommittees demanding more skilled community advocates. The community is also engaging more with basic science related HIV research. Increasing Australian participation in multinational trials efforts also requires more community involvement. This increased need paradoxically comes at a time of diminishing interest. Resourcing and skilling of new and existing community advocates will be a challenge for the 5th Strategy.

4.4. Care and Support

The efficacy of combination antiretroviral therapy has led to a decline in the AIDS mortality rate and an increasing number of people with HIV who are living longer.

Research conducted through the Australian Research Centre of Sex Health and Society shows that people with HIV are facing an increasing and more complex range of challenges relating to health and support needs. These include dealing with treatment failure and clinically intolerable

side effects, as well as mental health issues, poverty, isolation, housing problems and discrimination¹¹.

This research is confirmed by AFAO member organisations who report that clients are presenting with more complex and multiple needs. Care and support services provided through State/Territory AIDS Councils have moved away from a major focus on delivering palliative care services to a more diverse range of services to meet the current needs of people living with HIV/AIDS.

It is essential that policy, program and structure of service delivery be constantly monitored and adjusted. AFAO identifies the following issues as priority areas:

- An ongoing commitment to continued support for research into the ongoing health care and support issues of people with HIV/AIDS is essential to ensure that responses are effective and appropriate.
- Continuing support for policies that ensure identification of HIV/AIDS as a condition that requires specific approaches and strategies;
- Ongoing commitment to funding and support of community and non-government initiatives addressing the care and support needs of people living with HIV/AIDS;
- A strategy that includes the capacity to adjust to changes in the Australian epidemic and supports innovation in provision of care and support services;
- A commitment by the Commonwealth to support and consult with bodies representing people with HIV/AIDS and affected communities, when considering any changes to health and welfare policies and systems;
- A commitment to maintaining the current level of inclusion of HIV/AIDS drugs on the Pharmaceutical Benefit Scheme and continued support for inclusion of any future HIV/AIDS therapies in the scheme;
- Recognising the need for appropriate services for people with HIV/AIDS who also are experiencing a range of complex health impacts such as mental health and substance use issues; and
- Recognising the impacts of poverty and homelessness caused or exacerbated by HIV/AIDS.

Care and support services are primarily the funding responsibility of State/Territory governments. This has led to the lack of a nationally coordinated approach to care and support issues. Improved national leadership is essential if best practice in care and support is to be delivered nationally.

AFAO believes that the priorities and challenges identified in the 4th National Strategy for care and support which have largely been met are:

- Development of a coordinated continuum of care in most States/Territories through the development of HIV/AIDS Treatment and Care action plans; and
- Access to approved therapies and monitoring tools such as viral load testing.

However, it is clear that significant challenges remain and need to be addressed in the coming years. These are:

¹¹ Grierson, Misson, McDonald, Pitts, O'Brien, HIV Futures 3, ARCSHS 2002

- availability of and access to mental health services by people with HIV/AIDS and those at high risk remains a serious problem in many areas.
- access to adequate HIV-sensitive counselling has declined over the years.
- access to HIV/AIDS information and health care services in rural and remote communities - particularly access to HIV/AIDS drugs prescribing general practitioners - remains largely unsatisfactory.
- access to anti-retroviral drugs in rural and remote areas remains a concern.
- the shortage of section 100 HIV drug prescribers in some areas is of concern.
- improvements to access arrangements for antiretroviral drugs outside of hospital pharmacies has been minimal.

Some of these problems have been highlighted in the HIV/AIDS General Practice Enhanced Care Demonstration Project being conducted by the AIDS Council of NSW in conjunction with a range of general practices in Sydney. The outcomes of this project will provide a useful basis for assessing the program development needs in care and support for people living with HIV/AIDS and those at higher risk.

Recommendations:

That the HIV Committee review the outcomes of the HIV/AIDS General Practice Enhanced Care Demonstration Project and recommend policies and initiatives to be put in place by relevant service providers and government agencies arising from that review.

That the HIV Committee undertake a review of the adequacy of mental health services provision to people with HIV/AIDS and those at high risk.

4.5. Commonwealth Government's Welfare Reforms

In July 2000 the Government report on the review of the Australian welfare system, "Participation Support for a More Equitable Society" (the "McClure Report") was released. The report recommends many wide-ranging reforms to Australia's welfare system. The government has not formally responded to the report to date. Although the Government has begun implementing changes to the welfare system it has not clearly articulated an agenda or timeframe for implementation of the report's recommendations.

This lack of a formal and clear response from the Government has meant there is an environment of uncertainty about what changes will occur and when, and how they will impact on people living with HIV and AIDS. The reforms to the welfare system will potentially have a significant impact on people living with HIV and AIDS. A national survey of PLWHA, released in May 2002, reports that 49% of respondents receive a government pension or benefit and over one half of those on benefits are living below the poverty line.¹²

Living with a chronic illness requires significant financial outlays not only for primary therapies but additional costs for purchase of medicines related to secondary conditions as well as complementary therapies. Living with HIV also reduces a person's capacity to participate fully in the workplace and in many cases prevents people from working at all.

¹² HIV Futures 3 - Positive Australians on Service, Health and Well Being, Grierson et al, May 2002

People living with HIV live with a chronic and variable illness and the welfare system must be able to respond appropriately and flexibly to the needs of people with HIV in response to their condition. While AFAO does not oppose review of or changes to the welfare system, any changes should support and enhance quality of life.

As part of the 2002/2003 Federal Budget the Commonwealth Government announced changes to the eligibility criteria for Disability Support Pensions(DSP). Currently, the qualification for DSP includes a requirement that the person be unable to work at least 30 hours per week. Under the new rules announced in the Budget, this requirement will be tightened to 15 hours per week. These proposed changes potentially threaten the quality of life of people with HIV and AIDS through reduced income and more stringent applications of work capacity assessments without regard for the particular variables of HIV/AIDS. The current system allows a relatively smooth transition between work and welfare for those people living with HIV/AIDS who have some work capacity. It is likely that the proposed changes will prove to be a disincentive for some people living with HIV/AIDS who wish to return to the workforce.

Recommendations:

That the Government articulate a clear agenda for reform of the welfare system which includes mechanisms for community input into the process.

That the special circumstances of HIV/AIDS and other chronic illnesses must also be taken into account, when considering changes to the welfare system.

4.6. An Enabling Environment

Successive National Strategies have sought to create a supportive social and legal environment that encourages HIV-positive people and people whose behaviour might put them at risk to respond to education campaigns, and make use of services such as voluntary HIV testing, treatment, and care.

HIV/AIDS in Australia is a disease stigmatised as a gay man's disease or a disease of 'junkies'. Despite recent advances, discrimination against these groups — and in particular of people living with HIV/AIDS — remains a significant barrier to providing good quality health care and addressing the public health issues relating to HIV/AIDS.

The current national strategy recognises “an enabling environment” as a central element of Australia's response. It does this because “[t]he impact of HIV/AIDS extends beyond the clinical manifestations of illness to other factors such as housing, income support, discrimination, privacy, human rights, and Australia's participation in the global response to the virus ...”¹³.

An enabling social and legal environment is vital to delivering the objectives of reducing the incidence of and harm caused by HIV/AIDS. The impact of the epidemic for people living with HIV/AIDS include:

¹³ *Challenges and Changes: National HIV/AIDS Strategy 1999-2000 to 2003-2004*. Commonwealth Department of Health and Aged Care, Canberra.

- higher rates of poverty¹⁴;
- increased difficulties with housing¹⁵;
- lower rates of employment¹⁶; and
- significant rates of mental illness¹⁷

Numerous studies note the correlation between socio-economic status and access to health services¹⁸. Discrimination and marginalisation compound the difficulties of maintaining good health for affected communities, particularly people living with HIV/AIDS. Thus while stigma and discrimination are deleterious to the individuals concerned, they also result in a population health issue that has been recognised in previous Strategies — that combating the effect of an infectious disease requires us to maintain a low pool of infections to prevent further harm from HIV/AIDS in the community. A supportive legal and social environment is vital to ensure that population health goals are achievable.

The 1992 report by the Intergovernmental Committee on AIDS' Legal Working Party²⁰ continues to provide a solid blueprint for HIV/AIDS-related law reform in Australia, but there has been insufficient progress in implementing the blueprint. A report by ANCARD (as it then was) on implementation of the Legal Working Party's recommendations, based on self-reporting by all jurisdictions, was published in 1999. The report found that progress on achieving reforms had been "slow and generally unsatisfactory"²¹, with less than half of the recommended reforms implemented.

There was little progress on HIV/AIDS-related law reform at the national level during the 3rd National Strategy. There has been an increase in legal policy and advocacy output through the national ANCAHRD structure during the 4th National Strategy, following the reconstitution of the ANCAHRD Legal Working party. The Legal Working Party has functioned effectively in developing and disseminating HIV/AIDS-related legal policy, through its role as adviser to ANCAHRD and the Department of Health and Aging on the legal aspects of Australia's response to HIV/AIDS and Hepatitis C. Developing a Rights Analysis Instrument to measure the extent of compliance with the *International Guidelines on HIV/AIDS and Human Rights* was a significant output of the Legal Working Party.

AFAO welcomed the re-establishment of the ANCAHRD Legal Working Party, and the secretariat resources made available to it by the Department of Health and Aging. We see these

¹⁴ *HIV Futures 3*, published by the Australian Research Centre in Sex, Health and Society in May 2002, reported (at p.99) that over 30 percent of people living with HIV/AIDS in Australia live below the poverty line.

¹⁵ *HIV Future 3* reported (at p.99) that 52.7 percent of people living with HIV/AIDS in Australia experienced difficulty meeting the cost of housing.

¹⁶ *HIV Future 3* reported (at p.99) that slightly less than half of respondents (N= 898) identified their main source of income as a government benefit or pension.

¹⁷ *HIV Futures 3* reported (at p.46) that over 25 percent of respondents had used a mental health service in the previous 6 months.

¹⁸ For example Australian Institute of Health and Welfare, *Australia's Health 1998* at p.2.

¹⁹ *Challenges and Changes: National HIV/AIDS Strategy 1999-2000 to 2003-2004*. Commonwealth Department of Health and Aged Care, Canberra.

²⁰ Department of Health, Housing and Community Service. *The Final Report of the Legal Working Party of the Intergovernmental Committee on AIDS*, 1992.

²¹ *Status Report on Implementation of the Final Report of the Legal Working Party*. Australian National Council on AIDS and Related Diseases, Canberra, June 1999.

as positive steps by ANCAHRD and the Department towards promoting an enabling environment. AFAO has actively participated in the Legal Working Party's work.

However it is clear that the substantial output of the Legal Working Party has not translated to any significant extent into legal and policy reforms by governments and their departments. Neither ANCAHRD nor other members of the partnership have had success in promoting positive reforms to enhance the enabling environment and Australia's overall response to HIV/AIDS.

In some cases governments have proposed reforms which have had the potential to undermine the effectiveness of Australia's enabling environment. Two examples are South Australia's *Medical Practice Bill 2000* and proposed changes to Norfolk Island's immigration laws, both of which are discussed below.

Much of the content of the Final Report of the Legal Working Party concerns matters within the jurisdiction of the States and Territories, and developments in these jurisdictions are examined in the following section.

The States and Territories

There have been significant legislative reforms, and proposals for reform, at the State and Territory level, with the potential to alter the enabling environment. In some cases reforms have made a positive contribution to the response to the epidemic, but in other cases they haven't. The following developments have taken place during the 4th National Strategy:

- *Recognising same sex relationships*
 - The Final Report of the IGCA Legal Working Party recommended that legal recognition should be given to partners in non-traditional domestic relationship, which should include homosexual relationship.²²
 - The NSW Parliament passed the *Property (Relationships) Legislation Amendment Act 1999*. This Act changes the definition of "de facto relationship" to include same sex couples. NSW now recognises same sex relationships for the purposes of State superannuation schemes, but retains discriminatory age of consent laws, with an age of consent for male to male sex of 18 years, compared to 16 years for heterosexual and lesbian sex.
 - The Victorian parliament also passed legislation to recognise property and other rights arising out of same sex relationships, including rights under State superannuation schemes.
 - The Queensland parliament passed legislation recognising property rights in same sex relationships.
 - The Western Australian parliament passed legislation which creates an equal age of consent for homosexual and heterosexual sex of 16 years, and prohibits discrimination on the ground of sexual orientation including in access to fertility services. The legislation also recognises same sex relationships for the purposes of State superannuation schemes.

²² Recommendation 5.3 at p.44.

- *Drug law and policy reform*

- Through the Council of Australian Governments, all Australian governments agreed on a coordinated approach to diversionary schemes, and the Ministerial Council on Drug Strategy has endorsed these schemes. Diversionary schemes aim to avoid court proceedings, and the possibility of custodial sentences for people apprehended for minor drug offences, and encourage drug users to access drug education and treatment. Diversionary schemes are being implemented in most jurisdictions, with each jurisdiction developing its own approach.
- As a result of the NSW Drug Summit, held in 1999, a trial of a safe injecting room is now being conducted in Sydney. NSW has established “drug courts”, which aim to divert users of illicit drugs charged with a criminal offence away from incarceration and into drug treatment.
- Most jurisdictions have seen an increase in the availability of drug treatment services. In particular, there has been an increase in the availability of youth drug and alcohol services, using funds available through the National Illicit Drugs Strategy. The introduction of Bupronorphine and naltrexone has added some capacity and diversity in treatment options. However, no jurisdiction has increased the availability of drug treatment services to the point where the services are capable of meeting demand for drug treatment.
- Finalising the Indigenous Substance Misuse Strategy was a positive step towards addressing harms associated with substance misuse in Indigenous communities.
- In response to a finding of the Federal Court that illicit drug use could be covered by disability discrimination legislation, the NSW Government amended its *Anti-Discrimination Act* to exclude discrimination against drug users from the Act. The only real effect of the amendment is to promote prejudicial attitudes towards users of illicit drugs.
- High-intensity policing, such as the continued use of sniffer dogs in NSW (found to be illegal by that State’s Supreme Court, but subsequently legalised by State Government legislation), has been shown to have adverse consequences for health promotion in the context of drug use. High intensity policing promotes behaviours such as “take all your drugs at the one time” rather than risk carrying any on your person. This produces an increased risk of drug overdose.
- The development of the first National Hepatitis C Strategy, and the funding of programs under that strategy, has been complementary to health promotion efforts developed in the context of HIV and injecting drug use.

- *Sex industry law reform*

There is a lot of legislative energy directed to regulating Australia’s sex industry. Proposals and reforms have varied widely, but it is not uncommon for them to include features which hamper HIV prevention and sexual health promotion. Developments which have occurred during the 4th Strategy include:

- Tasmania: An inquiry has recommended reform of that State’s sex industry laws. Currently prostitution *per se* is not illegal but all other aspects of the sex industry remain illegal in that State, making health promotion work with sex workers very difficult.

- Queensland: The State Government legalised some aspects of the sex industry, subject to a high degree of regulation. Some features of the new legislative regime have the potential to undermine health and safety for sex workers.
- South Australia: Five Bills to amend that State's sex industry laws were debated but none enacted. Sex workers in that State report that the South Australian Vice and Gaming Squad regularly raids sex industry establishments and uses the presence of safe sex materials such as condoms, lubricant, and printed sexual health resources, as evidence with which to secure convictions for criminal offences related to prostitution. Police action like this hampers HIV prevention and health promotion in the South Australian sex industry.
- Western Australia: Several Bills were debated, and the *Prostitution Act 2000* was passed, to commence on 29 July 2000. The unwarranted emphasis on child prostitution and child sexual exploitation reinforces stigmatisation and discriminatory attitudes towards sex workers and the sex industry.

The Federal jurisdiction

While much of the law reform needed to achieve an "enabling environment" lies within the jurisdiction of the States and Territories, there are several matters which fall within the Federal jurisdiction. Federal laws continue to impact on the effectiveness of the response to HIV/AIDS, and these include laws which ignore same sex relationships or fail to provide protections against discrimination on the ground of sexuality. In a positive step, privacy protections under Federal law have been extended to the private sector.

- *Discrimination against same sex couples in superannuation law:* Some States have legislated to recognise same sex relationships for the purposes of State superannuation funds. However the great majority of superannuation funds are regulated by Federal law. A Federal Private Members Bill which would have gone some way towards removing discrimination against same sex couples (the *Superannuation (Entitlement of Same Sex Couples) Bill 2000*) was not supported by Government members in the Federal Parliament. A recent Federal legislative amendment has empowered superannuation funds to alter their rules so that members have greater scope in nominating a beneficiary in the event of the member's death, but this has had little impact on the rights of surviving same sex partners.
- *Protection against sexuality discrimination:* There is no anti-discrimination legislation at the Federal level which protects against discrimination on the ground of sexuality.
- *Privacy protection:* The Federal Parliament passed the *Private Sector Privacy Act (2000)* which extended Federal privacy protection to information held in the private sector. The legislation was accompanied by guidelines on health privacy in the private sector, produced by the Office of the Federal Privacy Commissioner.

Access to legal remedies for discrimination

While Australian legislation provides mechanisms to redress HIV/AIDS discrimination, access to these mechanisms has diminished in recent years. Research commissioned by the ANCAHRD Legal Working Group²³ showed that while complaints to the Human Rights and Equal Opportunity Commission under the Federal *Disability Discrimination Act 1992* had declined by 52 % between 1994 and 1998, there was a general upward trend in disability complaints to the NSW Anti-Discrimination Board. Funding cuts to both HREOC and to legal aid have contributed

²³ Cabassi, J. *Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV*. ANCAHRD Occasional Paper No. 1, May 2001.

to decreased use of the national human rights body by people with disabilities. In 1997, funding to HREOC was cut by approximately 43 %, resulting in delays in processing discrimination complaints which discourage people from using HREOC's services.

At around the same time, government funded legal assistance was reduced by \$120 million per year. There is now little legal aid funding for civil cases, including discrimination cases. For many people living on low incomes, legal redress for discrimination is increasingly out of reach.

Recommendations:

That Commonwealth funding for legal aid be increased for complaints under the *Disability Discrimination Act 1992* so that complainants who cannot afford the cost of legal representation are not denied access to legal remedies for discrimination.

That funding be made available for new community education initiatives that promote awareness of anti-discrimination laws, and the remedies such laws can provide.

Other law reform

Two examples which occurred during the 4th Strategy illustrate the need to actively define and promote the enabling environment - and to ensure there is political commitment to achieving and maintaining that environment:

- In 2000 the South Australian Government introduced the *Medical Practice Bill* into Parliament. This was a particularly ill-considered piece of legislation that would have required all medical practitioners to be regularly tested for HIV, and the resulting information made available to members of the public in some form on the website of the State Medical Registration Board. Medical practitioners who tested positive were to be subjected to restrictions on their right to practise. The proposal was the subject of vigorous objection and lobbying by the AIDS Council of South Australia, ASHM and ANCAHRD. After passing through the Lower House, the Bill lapsed due to an election being called. The Bill disregarded many of the principals which underpin an effective response to the HIV epidemic, such as the importance of universal infection control, privacy and confidentiality, and respect for the human rights of people living with HIV.
- In 2002 a member of the Norfolk Island Legislative Assembly proposed amending the island's immigration law to prohibit anyone with HIV, Hepatitis B, or Hepatitis C, from settling permanently on the island. The rationale for the proposed law was that the island's health care system could not cope with the burden of residents with these health conditions. It became apparent to AFAO during the course of lobbying against the proposal that there were very few chronic or life-threatening conditions with which the island's health care system could in fact cope. The singling out of these blood borne viruses for special treatment under the island's laws reflected the stigma and discrimination which are still attached to HIV and Hepatitis C. AFAO's efforts were key to having consideration of this Bill deferred.

Maintaining and improving an enabling environment

The overarching challenge Australia faces in promoting an enabling legal environment is the waning impetus for reform. There is a perception among governments that we have "dealt with" HIV, and that we no longer face the crisis of the early years of the epidemic. There is an

unwillingness to adopt the innovative legal and social policy initiatives which characterised the early Australian response, and which have since been replicated by governments in a large number of other countries.

With the aim of reinvigorating our efforts around improving the enabling environment, ANCAHRD commissioned a rights analysis instrument²⁴, designed to measure the extent to which Australian law and policy complies with the *International Guidelines on HIV/AIDS and Human Rights*. The International Guidelines were released jointly by UNAIDS and the United Nations High Commissioner for Human Rights in 1998. In Australia, a Rights Analysis Instrument was first used to audit mental health laws, and with support from the Australian Health Ministers' Advisory Council resulted in significant improvements in mental health laws.²⁵

A legislative audit exercise is needed in relation to the enabling environment. If we are to make progress, then all levels of government, and all key members of the partnership must be involved in a renewed effort. A recent grant from the AIDS Trust of Australia will permit audits to take place in each jurisdiction, and the active participation of all stakeholders including governments, bureaucracies, and affected communities, will be sought. It is not clear at the time of writing what degree of involvement can be expected by governments in each jurisdiction. In the example of mental health laws (see footnote), the process was conducted with the agreement and involvement of all relevant Ministers through the Australian Health Ministers' Advisory Council.

Substantial areas of legislation and practice still warrant attention:

- Sex industry laws in some States/Territories still take a prohibitionist approach, making health promotion for sex workers difficult. One representative of sex workers has described the current legal framework as a “disabling environment”.
- In some jurisdictions, the age of consent for male-to-male sex is higher than for opposite sex partners and lesbians. Unequal and discriminatory age of consent laws hinder HIV education initiatives targeting young same sex-attracted men and contribute to low levels of self-esteem, increasing the potential for HIV transmission.
- There is no nationally consistent approach to the use of the criminal law where reckless or negligent transmission of HIV is alleged.
- For same sex couples, the death toll from AIDS among gay men has vividly exposed the discrimination against same sex couples in laws governing most superannuation funds, and in retirement income laws.
- People in custodial settings do not have access to the means of blood borne virus prevention, and treatment and care services on an equal footing with the general community.

²⁴ Watchirs, H. *A Rights Analysis Instrument to Measure Compliance with the International Guidelines on HIV/AIDS and Human Rights*. Australian National Council on AIDS, Hepatitis C and Related Diseases, Canberra, November 1999.

²⁵ In 1996 an instrument was developed to evaluate Australian legislation on the treatment of people with a mental illness against international human rights norms, for the National Mental Health Working Group of the Australian Health Ministers' Advisory Council. The process established in mental health was that each Health Minister convened a multi-disciplinary panel to assess the existing level of compliance with the International Guidelines. Each panel consisted of a consumer, a human rights expert, a lawyer familiar with the subject matter, a non-government organisation service provider, a clinician, an advocate, a carer, and a government officer working in the relevant policy and program area. A national panel with similar representation would also be convened to consider each jurisdiction's self-assessment, with a view to promoting consistency in scoring. State and Territory governments gave a commitment under the National Mental Health Strategy to enact legislation that was in compliance with international human rights norms by 1998.

- Australian migration law continues to discriminate against people with HIV/AIDS.
- Public health legislation in some jurisdictions (for example Western Australia) is outdated and does not provide an optimum framework in which to respond to HIV.
- Many of the recommendations in the Legal Working Party's final report regarding injecting drug use (for example review of laws prohibiting possession of drug-related equipment other than needles and syringes; repeal of the offence of self-administration) have not been implemented.

Reform in these areas is necessary if we are to sustain our response to date, and improve it in the future. Strong Commonwealth leadership, particularly using a whole of government approach, is needed to improve the enabling environment underpinning Australia's HIV/AIDS response.

Recommendation:

That the Minister for Health, in conjunction with other relevant Ministers, establish and resource a national audit process, as outlined above, to measure each jurisdiction's compliance with the International Guidelines on HIV/AIDS and Human Rights, and to promote reforms which will enhance Australia's enabling environment.

4.7. Research

AFAO has produced a comprehensive analysis of the significance, performance and future of Australia's HIV Research Program in our submission to the Strategies Review Research Panel. The document contains 26 recommendations relating to the future of the research program. (A copy of these recommendations are attached at Appendix C of this submission.)

We urge members of the Lead Review Team and members of the HIV and Hepatitis C Review Teams to consult our Research Program submission in conjunction with this submission (which covers all aspects of Australia's HIV response). A brief summary of the key points and recommendations from our Research program submission follows.

- Australia is experiencing changes to a set of factors which shape the impact of the HIV epidemic. The confluence of these changes has the potential to significantly worsen the epidemic's impact. Therefore sustaining our HIV research effort is essential if we are to respond to difficult and complex challenges in HIV prevention, treatment, care and support.
- Australia's research effort is programmatically integrated with all parts of Australia's response to HIV – in clinical care and trials, early access to new treatments, evidence-based prevention and support program development. This reflexive programmatic integrity is one of the key foundations of Australia's successful response – and widely admired in other comparable countries. Down-grading the research program or shifting it to the National Medical Health and Research Council (NHMRC) - would jeopardise Australia's response overall.
- Transferring the program to the NHMRC would down-grade its contribution substantially. The current program has an excellent record of delivering timely research findings in response to questions and issues arising directly from the strategic objectives

and policy outcomes set by the HIV/AIDS Strategy and required by program delivery agencies, whether government, community sector or health care sector.

- The NHMRC operates in a fundamentally different framework, where research is primarily driven by the individual investigator operating within a competitive application process. This makes timelines for research outputs highly unpredictable and it largely removes input to the research from those who need the answers to guide program development and delivery. This model of research funding is therefore inappropriate to deal with emerging and volatile communicable diseases such as Hepatitis C and HIV.
- Under the current arrangements Australia has developed an outstanding record in HIV research. In particular, the National HIV Research Centres have performed exceptionally well. Their work continues to play a key role in underpinning Australia's response to the epidemic. This performance has been particularly meritorious given the environment in which the Centres have been operating in recent years – in particular, moves to “mainstream” HIV research into the NHMRC and confusion arising from a policy of combining approaches for HIV and Hepatitis C.
- Experience has now shown that overlap between HIV and Hepatitis C is significantly less than predicted or assumed by the drafters of the 4th National Strategy. Attempts at combining HIV and HCV policy development and programs have generally not been successful and the approach has weakened the national responses and research programs for both these conditions. Epidemiology has been the only area where substantial, beneficial overlap has emerged.
- Hepatitis C research should be supported through a separate funding and research structure, including a Hepatitis C scientific advisory committee to guide HCV research. A dedicated, separately organised and separately funded HIV research response should be maintained.
- Dedicated funding and support for the National HIV Research Centres should be continued for at least 7 years. Further moves to “mainstream” HIV research into the NHMRC should be deferred for 7 years and revisited at that time if appropriate.
- For the foreseeable future, funding, governance and reporting structures for HIV research should remain under the administration of the Population Health Division of the Commonwealth Department of Health and Ageing. The HIV research program should be informed by advice from National Centres' Scientific Advisory Committees, relevant governmental advisory structures and other stakeholders.
- The Population Health Division should have direct access to clearly designated funding to enable HIV research to be commissioned as needed to meet emerging threats and challenges, based on advice received.
- Funding levels for the HIV research program should be examined, especially in light of infrastructure and other cost increases. In particular, the budgets of the National Centres in HIV Research should be adjusted where necessary to address any erosion in real terms from these cost increases.

- Australia's future HIV research effort should ensure appropriate funding and organisational mechanisms to support investigator-initiated research.
- An Australian HIV Vaccine Initiative (AHVI) should be established to provide a national coordination mechanism for Australia's role in HIV vaccines, bringing together the policy, political and strategic dimensions of research, industry and overseas development.
- Australia will be increasingly expected to assist and support research efforts aimed at combating the worldwide impact from HIV/AIDS. As part of this, the National HIV Research Centres need to be encouraged and supported to assist HIV research efforts in other countries, especially developing nations in our region.
- Now is not the time to weaken Australia's HIV research capacity. On the contrary, our HIV research program should be strengthened given the very substantial challenges of HIV nationally, regionally and globally.

4.8 International & Regional Responsibilities

The leadership role that countries like Australia can play in promoting guiding principles for effective global HIV responses are articulated in Australia's National HIV/AIDS Strategy, in the UNGASS Declaration of Commitment (2001) and the Asia/Pacific Ministerial Statement on AIDS (2001). These principles, if adopted, would significantly contribute to the global and regional response to HIV/AIDS. Key principles include:

- Supporting the partnership model;
- Involving affected communities;
- The centrality of people living with HIV/AIDS in an HIV/AIDS response;
- An HIV and development approach;
- The respect for human rights of PLWHA and vulnerable groups; and
- An enabling environment.

Australia has recognised the gravity of the global HIV epidemic and is providing assistance through targeted programs aimed at reducing spread of HIV and mitigating the impact on individuals and societies. The leadership of the Minister for Foreign Affairs through a range of initiatives has been a particularly welcome development.

However, given the burgeoning global epidemic and concomitant threats to economic and political stability, Australia has an obligation to continue its strong leadership, and maximise provision of resources.

Australian community based organisations like AFAO continue to play an important role in assisting global and regional community-based HIV responses. AFAO has been playing an increasing role in helping with formulation of regional and global HIV policies, plans and other initiatives. Examples of this work include –

- substantial input through the Australian delegation to United Nations General Assembly Special Session on HIV/AIDS (UNGASS);

- proposing structures to assist the implementation of the UNGASS Declaration of Commitment; and
- contributing to strategic plans and responses to HIV/AIDS at regional and global levels.

Resourcing for AFAO's regional and international work is very limited, and this work is not recognised in the current Strategy. We are experiencing difficulties in sustaining our regional and international work. Further government support is needed to allow AFAO to continue and expand its contribution to regional and global responses.

AFAO actively supports community-based and driven work in the Asia-Pacific region. Work that links expertise and resources between community-based organisations in Australia and countries in Asia-Pacific should be expanded, with the aim of building local capacity to manage and administer prevention, care and support programs for people living with HIV and communities affected. It is also necessary to build the community-based responses which are lacking in many countries in the region to assist in the formation of an effective partnership approach.

As a signatory to the UNGASS Declaration and the Asia/Pacific Ministerial Statement, Australia will be expected to show continuing leadership in the global HIV/AIDS response. Australia played a leading role at the forums that produced these documents. Australia's role in promoting regional leadership through a leadership forum, as announced at the 6th International Congress on AIDS in Asia and the Pacific (ICAAP) is commendable. This regional leadership role is necessary not only to protect national interests but also to support growth and security in the region.

We have a particular role to play in Asia-Pacific. Asia-Pacific has numerous examples where approaches to the prevention and control of HIV/AIDS have been hindered with denial and discrimination, particularly in relation to injecting drug use, sex work, and/or sex between homosexually active men. Australia's partnership approach to working with affected communities and supporting an enabling environment can contribute to regional HIV work as well as providing an example for other governments to undertake a similar approach. We commend Australia's support of the Coalition of Asia Pacific Regional Networks on HIV/AIDS which clearly demonstrates a partnership model with community-based organisations and communities that are affected by and vulnerable to HIV.

The key international and regional challenges listed in the 4th Strategy are:

- Support for health promotion including harm minimisation and condom distribution;
- Ethical treatment and vaccine trials; and
- Improving treatment access

All of these issues remain important. Rising infections among injecting drug users, notably in Asia-Pacific, require adoption of harm reduction programs including needle and syringe programs and peer education programs for injecting drug users. The Australia-Thai collaboration for a preventative HIV vaccine will involve a vaccine trial in Thailand. Other important clinical trials in the region for HIV treatments are also underway. Treatment access has been noted by AusAID in recent policy and should be given particular attention in any current discussions of international assistance and cooperation. Australia's domestic experience with HIV treatment issues, its role in the region and its facilities for clinical and social research means that - with adequate support - we have a crucial role to play in regional treatment and care issues.

Australia's major bilateral projects should be monitored and examined to ensure that the partnership model is reflected in this work, and that the community sector has a key role.

The priorities of the international aid program also require it to be consistent with and reflect Australia's commitments made in the UNGASS Declaration and the Asia-Pacific Ministerial Statement.

The 4th Strategy states that "*mechanisms for coordinating the international work of partnership members will be explored during the term of this Strategy*". This recommendation is yet to be actioned. Consequently, international and regional HIV/AIDS work in Australia is not particularly well coordinated.

A key question in addressing this is where responsibility lies for regional and global HIV policy development in the Commonwealth Government. Consideration should be given to strengthening the capacity of the Department of Foreign Affairs and Trade to undertake this work, with mechanisms identified to provide input from the community sector and other parties.

Recommendations:

That in light of the burgeoning global epidemic and concomitant threats to economic and political stability, Australia maintain its strong leadership in the global fight against HIV and maximise provision of resources to support this.

That more formalised support be given for Australia's contributions to regional and global HIV policy development, including through the work of community based organisations.

That lines of responsibility for regional and global HIV policy development in the Commonwealth Government be examined and formalised.

Abbreviations

ACON	AIDS Council of New South Wales
AFAO	Australian Federation of AIDS Organisations
AGIH	Advisory Group on International Health (of AusAID)
AHC	Australian Hepatitis Council
AIDS	Acquired Immuno-Deficiency Syndrome
AIVL	Australian Injecting and Illicit Drug Users League
ANCAHRD	Australian National Council on AIDS, Hepatitis C and Related Diseases
ANCD	Australian National Council on Drugs
ADB	Anti-Discrimination Board of New South Wales
ARCSHS	Australian Research Centre in Sex, Health and Society
ASHM	Australasian Society for HIV Medicine
ATSIC	Aboriginal and Torres Strait Islander Commission
AusAID	Australian Agency for International Development
CARG	Commonwealth AIDS Research Grant
CDNA	Communicable Diseases Network Australia
CTARC	Clinical Trials and Research Committee (of ANCAHRD)
CSIRO	Commonwealth Scientific and Industrial Research Organisation
DHA	Commonwealth Department of Health and Ageing
GP	general practitioner
HAART	Highly Active Anti-Retroviral Therapy
HREOC	Human Rights and Equal Opportunity Commission
HIV	Human Immuno-deficiency Virus
IASHC	Indigenous Australians Sexual Health Committee (of ANCAHRD)
ICAAP	International Congress on AIDS in Asia and the Pacific
IDU	Injecting Drug Use
IGCAHRD	Inter-Governmental Committee on AIDS, Hepatitis C and Related Diseases
IGCD	Inter-Governmental Committee on Drugs
LWP	Legal Working Party (of ANCAHRD)
NACCHO	National Aboriginal Community Controlled Health Organisation
NAPWA	National Association of People with HIV/AIDS
NCDC	National Centre for Disease Control
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NCHSR	National Centre in HIV Social Research
NCHVR	National Centre in HIV Virology Research
NESB	non-English speaking background
NHMRC	National Health and Medical Research Council
NIASHS	National Indigenous Australians Sexual Health Strategy
NIH (US)	National Institutes of Health
NPHP	National Public Health Partnership
NSP	Needle and Syringe Program
OATSIH	Office for Aboriginal and Torres Strait Islander Health
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PEP	Post-Exposure Prophylaxis
PHD	Population Health Division (of the Department of Health and Ageing)
PHOFA	Public Health Outcome Funding Agreement
PLWHA	People living with HIV/AIDS

ANCAHRD

Terms of Reference:

The Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) is the Federal Government's key advisory body on HIV/AIDS, hepatitis C and related communicable diseases that have clear and direct links to HIV/AIDS and/or hepatitis C. It is established to provide independent and expert advice to the Minister for Health and Aged Care, who appoints members on the basis of their expertise. It is principally concerned with the identification of national needs, objectives and priorities in the areas of education, treatment, services and research, and to take on a public information role on HIV/AIDS, hepatitis C and related issues in order to increase community understanding.

To consider and advise the Minister for Health and Aged Care on matters concerning HIV/AIDS, hepatitis C and related communicable diseases that have clear and direct links to HIV/AIDS, hepatitis C, such as STIs, including:

- national needs, objectives and priorities and the implementation of the *National HIV/AIDS Strategy 1999-2000 to 2003-2004* and the *National Hepatitis C Strategy 1999-2000 to 2003-2004*;
- emerging issues in the area and anticipated changes in the epidemics; education priorities, the treatment and care of people living with HIV/AIDS and people living with hepatitis C, and strategies for the prevention of HIV/AIDS and hepatitis C;
- current legal, medical, scientific, ethical, social and public health aspects; research activities, guidelines and priorities, ensuring that research undertaken relates to and helps achieve the goals set out in the *National HIV/AIDS Strategy 1999-2000 to 2003-2004* and the *National Hepatitis C Strategy 1999-2000 to 2003-2004*; and
- other matters referred to it by the Minister.

ANCAHRD is to produce a comprehensive work plan, in keeping with its terms of reference, which will be reviewed and updated annually. ANCAHRD will report annually to the Minister for Health and Aged Care against its work plan and on aspects of the implementation of the *National HIV/AIDS Strategy 1999-2000 to 2003-2004* and the *National Hepatitis C Strategy 1999-2000 to 2003-2004*.

ANCAHRD Responsibilities Listed in the 4th National HIV/AIDS Strategy:

1. The National Strategy will be put into effect through the work plans of the ANCAHRD and its committees.
2. ANCAHRD will continue to report to the Minister on the extent to which the Strategy is successfully implemented and how best to respond to the challenges that have been identified as well as those that emerge during the next five years.
3. ANCAHRD will advise the Minister for Health and Aged Care on the relevance and appropriateness of performance indicators and if necessary propose improvements for monitoring the Strategy's implementation.
4. ANCAHRD will continue to play a central role in identifying priorities and pressing for law reform under this National HIV/AIDS Strategy.

5. ANCAHRD will have a role in monitoring consistency in the application of harm-minimisation strategies and in recommending remedial action should this be required.
6. Under the National Strategy ANCAHRD will play a leadership role by establishing regular intersectoral forums to discuss and advance HIV/AIDS health promotion in correctional institutions.
7. Under the National Strategy ANCAHRD, along with other members of the partnership, will continue to press for reform of legislative frameworks and law enforcement practices that adversely affect the health of male and female sex workers or health promotion measures directed at these people and their clients.
8. ANCAHRD will continue to play a central role in establishing and monitoring standards of care.
9. ANCAHRD will continue to be responsible for liaising with the National Health and Medical Research Council in relation to the management of project grants and training awards, to ensure consistency with the priorities of the research program.
10. ANCAHRD will promote and support innovative interdisciplinary research and speculative research.
11. To capitalise on the benefits of vaccines for the prevention and treatment of HIV/AIDS, a coordinated national effort will be made: ANCAHRD will play a central part in coordinating this effort. The following will be the main components of the national vaccine effort:
 - a. A coordination system that integrates initiatives designed to reduce risk behaviours with initiatives relating to vaccines and treatment;
 - b. a commitment to build on Australian strengths in partnership responses, immunology, virology, clinical trials, socio-cultural analysis and community development, in a manner that returns value to the community that has invested in this research and development;
 - c. a commitment to conduct population efficacy trials of a coordinated prevention strategy that incorporates vaccines alongside education and treatment programs;
 - d. recognition that coordination is required both within and between vaccine, education and treatment programs.

HIV RELATED HEALTH PROMOTION FOR HOMOSEXUALLY ACTIVE MEN

HIV COMMITTEE – QUESTIONS PROPOSED TO THE IGCAHRD

Community Based Non-Government Organisations (including AIDS Councils)

1. Please list those community based non-government organisations receiving State/Territory Health Department funding to carry out specific HIV prevention activities targeting MSM (homosexually active men)?
2. For each of these organisations:
 - a. List the positions (full-time to half-time only), including the position title and a brief description of key activities, that are specifically dedicated to HIV prevention work targeting MSM.
 - b. List the funding for each of these positions.
3. Please indicate if one or more of the following activities are carried out by any of these positions:

A systematic program of regular liaison with venues (bars, nightclubs) frequented by MSM, for the purpose of having these venues display and promote up to date HIV prevention awareness information targeting MSM (safe sex, injecting drug use).

A systematic program of regular liaison with sex on premises venues (eg. gay saunas, sex clubs) and/or businesses where sex occurs (eg. sex video and sex aid shops), frequented by MSM, with the aim of having these venues promote up to date HIV prevention awareness information targeting MSM (display safe sex messages, ensure availability of condoms & lube, display safe injecting use messages)

A systematic program of regular visits to gay “beats” (toilets) on a regular basis with the aim of locating in these venues up to date safe sex messages targeting MSM.

A systematic program of activities (eg. peer education type group sessions, one on one counselling, group workshops) specifically aimed to promote and sustain safe sexual and safe injecting practices among MSM.

Any other systematic program of activities and/or dedicated specific positions promoting HIV prevention to –

Asian MSMs
Indigenous MSMs

Younger MSMs
Mature Aged MSMs

4. Please indicate whether the above activities are State or Territory wide, limited to specific cities, geographic regions, areas, etc.
5. Please give details of funding provided for the production of specific campaign materials, brochures and advertising to promote HIV prevention among MSM.
6. Other instructions:

Only provide details of obvious, specifically dedicated to MSM positions/activities.

Do not attempt to provide descriptions of diffuse or indirect activities which may reach some MSMs from time to time.

Other bodies/organisations (eg. Area Health Services, etc), including government or quasi government bodies

1. Which of these bodies/organisations carry out specific HIV prevention activities targeting homosexually active men?
2. For each of these bodies/organisations:
 - a. List the positions (full-time to half-time only), including the position title and a brief description of key activities, that are specifically dedicated to HIV prevention work targeting MSM.
 - b. List the funding for each of these positions.
3. Please indicate if one or more of the following activities are carried out by any of these positions –

A systematic program of regular liaison with venues (bars, nightclubs) frequented by MSM, for the purpose of having these venues display and promote up to date HIV prevention awareness information targeting MSM (safe sex, injecting drug use).

A systematic program of regular liaison with sex on premises venues (eg. gay saunas, sex clubs) and/or businesses where sex occurs (eg. sex video and sex aid shops), frequented by MSM, with the aim of having these venues promote up to date HIV prevention awareness information targeting MSM (display safe sex messages, ensure availability of condoms & lube, display safe injecting use messages)

A systematic program of regular visits to gay “beats” (toilets) on a regular basis with the aim of locating in these venues up to date safe sex messages targeting MSM.

A systematic program of activities (eg. peer education type group sessions, one on one counselling, group workshops) specifically aimed to promote and sustain safe sexual and safe injecting practices among MSM.

Any other systematic program of activities and/or dedicated specific positions promoting HIV prevention to –

Asian MSMs
Indigenous MSMs
Younger MSMs
Mature Aged MSMs

4. Please indicate whether the above activities are State or Territory wide, limited to specific cities, geographic regions, areas, etc.
5. Please give details of funding provided for the production of specific campaign materials, brochures and advertising to promote HIV prevention among MSM.
6. Other instructions:

Only provide details of obvious, specifically dedicated to MSM positions/activities.

Do not attempt to provide descriptions of diffuse or indirect activities which may reach some MSMs from time to time.

May 2002.

Appendix C.

Recommendations from AFAO's submission to the Strategic Research Review & Review of National & Collaborating Centres in HIV Research, 17 May 2002

Recommendations

1. That Australia's HIV research capacity be strengthened to meet the substantial challenges arising from HIV nationally, regionally and globally.
2. That dedicated funding and support for the National HIV Research Centres be continued.
3. That stronger linkages be established between NCHVR and NCHECR and between ARCSHS and NCHECR.
4. That Hepatitis C research be developed through a separately funded research centre/network, including the appointment of a HCV Research Director and a scientific advisory committee to oversight the HCV research program.
5. That the HIV Committee establish a process to review the current extent of research related to the impact of sexually transmitted infections on HIV progression and transmission, identify gaps, clarify priorities for further research and recommend how this research is undertaken.
6. That further steps towards "mainstreaming" HIV research be abandoned in the interests of maintaining an effective HIV response in Australia.
7. That the governance and reporting structures for HIV research remain under the administration of the Population Health Division of the Department of Health and Ageing, informed by advice from the National Centres' Scientific Advisory Committees, relevant governmental advisory structures and other sources.
8. That the Population Health Division have direct access to clearly designated funding to enable HIV research to be commissioned as needed to meet emerging threats and challenges, based on its own assessments and on advice received from advisory structures and key stakeholders.
9. That to end continuing uncertainty dedicated funding for HIV related research should be committed for a further period of 7 years.
10. That funding levels for the HIV research program be examined in light of infrastructure and other cost increases.
11. That the National Centre Scientific Advisory Committees have prime responsibility for ensuring that the Research Centres' workplans meet strategic objectives and priorities, including delineation of "strategic" vs "non-strategic research".
12. That each of the National Centres host a future directions and priorities workshop every two years.

13. That the outcomes of these biennial workshops should be reflected in a comprehensive research plan, which would inform Centre workplans and research activities commissioned from time to time by the PHD. An opportunity should be given for the research plan to be commented on by the Minister's HIV advisory committee.
14. That a similar model be followed for Hepatitis C, including establishment of a scientific advisory committee for a Hep C research network.
15. That future HIV research organisation and funding recognise the importance of supporting investigator initiated HIV research.
16. That appropriate mechanisms be identified to achieve a balance between investigator initiated and strategic (or targeted) HIV research.
17. That in line with AFAO's call for streamlining HIV advisory structures, Clinical Trials and Research Committee (CTARC) be disbanded and the provision of research advice allocated to the HIV Committee and the HCV Committee.
18. That clear role statements and terms of reference be developed for the HIV Committee and the HCV Committees clarifying their role in providing necessary advice on the HIV and HCV research programs.
19. That short, fixed term and purpose working parties be established by the HIV and HCV Committees to deal with any issues related to research that may arise that require additional expertise and consideration.
20. That the task currently vested in CTARC of approving individual research proposals (particularly clinical research studies) be devolved to the National Centres' Scientific Advisory Committees.
21. That standard of care protocols and treatment guidelines, and informational materials related to scientific, treatment and infection control issues (including ANCAHRD Bulletins) be developed by the Department of Health and Ageing itself or contracted out to appropriate bodies such as ASHM and AFAO.
22. That the current National HIV Research Centre model and structures be retained.
23. That in line with AFAO's recommendations to streamline research and advisory structures, the National Centre SAC's terms of reference be revised to clarify duties and responsibilities, particularly with respect to research priority setting, approving Centre workplans, reviewing operating budgets proposed by the Director; and providing other necessary advice as required by the Population Health Division.
24. That an Australian HIV Vaccine Initiative (AHVI) be established to provide a national coordination mechanism for Australia's role in HIV vaccines, bringing together the policy, political and strategic dimensions of research, industry and overseas development.
25. That future HIV research funding and organisational structures include mechanisms to enable the National Centres to further support and foster HIV research in developing countries, especially in Asia/Pacific.

26. That coordination and information exchange mechanisms for regional and international HIV research efforts involving Australia be identified.