

**2002 REVIEWS OF THE NATIONAL HIV/AIDS
AND HEPATITIS C STRATEGIES AND
STRATEGIC RESEARCH**

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PREFACE

HIV/AIDS and hepatitis C continue to cause significant levels of morbidity and mortality globally. Considerable burden is also placed on healthcare systems in managing these diseases. Surveillance data is now indicating increases in new HIV infections in some Australian States. Hepatitis C is now Australia's most commonly diagnosed notifiable disease. Also of particular concern to Australia is the rapid rise of HIV infection in the Asia Pacific region, especially in Papua New Guinea.

Australia is recognised for its international leadership in its comprehensive approach to managing these two diseases.

Australia's national approach to responding to HIV/AIDS has long been regarded as one of the best in the world. In 1989 the first National HIV/AIDS Strategy was developed, followed by successive Strategies leading up to the current 1999-2000, 2003-2004 edition. The current *National HIV/AIDS Strategy 1999-2000 to 2003-2004* provides a five-year framework for strategic directions and coordinated action on HIV/AIDS. As it is Australia's fourth HIV/AIDS strategy, it builds on knowledge about combating the HIV virus accumulated over the past two decades.

Australia also leads the international community in having developed a 'world-first', pioneering, strategic document that establishes important foundation for action to guide the national response to the growing hepatitis C epidemic. The *National Hepatitis C Strategy 1999-2000 to 2003-2004* is Australia's first comprehensive framework for national action to address the hepatitis C epidemic.

To ensure that Australia's strategic management of HIV/AIDS and hepatitis C is based on the most up to date scientific evidence, the Commonwealth continues to fund research and encourage collaborations with relevant overseas experts. The Strategic HIV/AIDS, Hepatitis C and Indigenous Sexual Health Research Program and the National and Collaborating Centres in HIV Research, are key research organisations that have significantly contributed to informing government policy and innovative advancements in treatment for those affected by HIV/AIDS and hepatitis C.

In February 2002, Senator the Hon Kay Patterson, the Commonwealth Minister for Health and Ageing, requested independent reviews of the National HIV/AIDS and Hepatitis C Strategies to be undertaken concurrently with the quinquennial reviews of the National Centres in HIV Research. The reviews were conducted through a single process, led by an overarching 'Lead Review Team' chaired by Professor Andrew Wilson. Small review panels were appointed to work on each of the specific review exercises. In broad terms, the Review Teams were asked to assess the extent to which the Strategies recommendations and guiding principles have been implemented or adopted and their appropriateness; and to provide advice that will inform the next phase of Australia's response to HIV/AIDS and hepatitis C. Each Review Panel prepared an individual Report and these have been published together as separate chapters.

The first chapter of the Report provides an overview of the Reviews compiled by the Lead Review Team, drawing together the key recommendations of the other individual Reports and the input of the Reference Panel.

**REVIEW OF THE NATIONAL HIV/AIDS AND HEPATITIS C
STRATEGIES: REPORT OF THE LEAD REVIEW TEAM**

**A JOURNEY WELL STARTED BUT NOT
FINISHED**

October 2002

**Professor Andrew Wilson
Mr Nicholas Partridge OBE
Associate Professor Liviana Calzavara**

1.1 SUMMARY

The reviews of the National HIV/AIDS Strategy 1999–2000 to 2003–04, the National Hepatitis C Strategy 1999–2000 to 2003–04 and the 2002 Strategic Research Review were undertaken to assess the progress of the strategies and to determine the need for and the directions of subsequent strategies and research activity.

The review process involved a scientific review of each of the National Centres in HIV Research and separate reviews for HIV/AIDS, hepatitis C and strategic research. The role of the Lead Review Team is to provide advice to the Commonwealth Minister for Health and Ageing in order to inform the next phase of Australia's public health response to HIV/AIDS and hepatitis C, including their relationship to other communicable diseases and broader sexual health matters. As part of its task, the Team has prepared this report, which draws together the reports of the individual reviews and the input of the Reference Panel to make recommendations for future priorities and directions.

1.1.1 HIV/AIDS

Australia has received international acclaim for the quality and strength of its HIV/AIDS response, as guided by its three previous national strategies. The fourth National HIV/AIDS Strategy is again serving us well in achieving a coordinated, efficient partnership approach to the control of HIV and the care and treatment of people living with HIV/AIDS. Indeed—given early and worrying indications that risk behaviour is increasing and the fact that in at least one Australian State HIV transmission rates have increased—the primary challenge for the next national strategy will be to overcome complacency produced by past successes and revitalise Australia's efforts to control HIV.

Worldwide, the HIV epidemic is spreading mainly through sexual transmission. In Australia, the spread is occurring mainly among men who have sex with men. This population is heterogeneous in terms of age, sexual interests, knowledge of HIV and safe sex, and the degree of identification with the gay community. Recognition of this needs to be a strong feature of the next strategy.

The increasing incidence of sexually transmissible infections (STIs) in Australia, the biological synergy between STIs and the risk of HIV, and the small but growing number of heterosexually acquired HIV infections also give cause for concern locally. Another important factor that should be considered in Australia's future response to HIV is the growing number of people living with HIV and the implications this has both for prevention and treatment and care services and for the community organisations that deliver these services. Although sexual transmission continues to be the main source of infection, there is also a real and continuing risk that HIV infection might become established among injecting drug users: once established in this group, the virus would be very difficult to control.

The Lead Review Team recommends the expedient development and implementation of a fifth National HIV/AIDS Strategy that, among other things, has the following features:

- ◆ a major prevention education program focusing on men who have sex with men—who continue to constitute the group at greatest risk
- ◆ complementarity with a national prevention and education program promoting safe sex to the general community—that is, a program aiming to prevent STIs
- ◆ a stronger focus on the complex and diverse needs of people living with HIV—including their mental and social health.

The Lead Review Team also recommends a re-evaluation by the key community partner organisations—gay, injecting drug user, and sex worker organisations—of their constituencies, roles and priorities, particularly in relation to prevention of HIV and STIs and the care of people living with HIV/AIDS. These organisations are vital to Australia's response to HIV, and there may be a need to re-invigorate their involvement in programs of prevention, support and care.

The Lead Review Team further recommends that—in the face of the global HIV epidemic, which is increasingly affecting our near neighbours—a whole-of-government policy on Australia's international role, responsibilities and responses be developed.

1.1.2 Hepatitis C

Australia achieved a 'world first' with its National Hepatitis C Strategy. In developing the strategy, it acknowledged that, while the visible burden of disease is growing now, it is necessary to act to prevent an even greater burden for future generations. The principal cause of hepatitis C infection in Australia is injecting drug use, and the strategy appropriately recognised this. But the available evidence suggests that the strategy has had little effect in controlling the epidemic.

The essential components of the strategy are developing partnerships and involving affected communities, access and equity, harm reduction, health promotion, research, surveillance, and linked strategies and infrastructure. There is substantial room for improvement in every one of these areas and—given the size of the problem—at least some of them have been under-resourced.

Moreover, the strategy inadequately recognises that a very large infected and undiagnosed population continues to fuel the epidemic. Until the size of this pool is reduced, progress will be difficult to achieve. There appear to be substantial barriers to wider access to treatment: greater accessibility could play an important part in controlling the epidemic by reducing the size of the infective pool.

The Lead Review Team recommends the immediate development of and increased resourcing for a second National Hepatitis C Strategy that, among other things, has the following features:

- ◆ a program to improve the maintenance of and expand a broad range of harm-reduction strategies—including examination of other approaches to reducing injecting behaviour

- ◆ development and implementation of specific programs for prevention of the spread of, and the use of treatment for, blood-borne viruses in prisons
- ◆ expansion of peer education
- ◆ resourcing of a specific research program that incorporates the factors that will inform policy and practice—including the epidemiological, social and cultural aspects of risk and transmission and the barriers to seeking treatment.

Because of the role of injecting drug use in the hepatitis C epidemic, the need for links with the National Drug Strategy is obvious. The Team recommends a greater focus within the National Drug Strategy on the broader health concerns of injecting drug users, including hepatitis C.

Hepatitis C is grossly under-reported in statistics on notifiable diseases: if the impact of intervention programs is to be monitored, it is extremely important that methods of surveillance be improved.

Discrimination against people with hepatitis C is widespread, and a process should be developed whereby the national implications of the findings of the New South Wales Anti-Discrimination Board's 2001 enquiry into hepatitis C-related discrimination can be assessed.

The people most affected by hepatitis C are largely marginalised in our society, without much of a voice. It is essential that the medical and public health community acknowledge and embrace the fact that the hepatitis C epidemic is a public health problem of national significance. Moreover, the Lead Review Team is of the view that the size of problem and the consequent need to lift its profile are such that the second strategy should be guided by a separate ministerially appointed committee.

1.1.3 Research

All aspects of Australian HIV research—social, epidemiological, clinical and virological—have earned international recognition.

The HIV/AIDS strategies have gained much from the investment in the National Centres in HIV Research. There is, however, room for review of the current priorities for investment in the centres and of the potential benefits of moving some aspects of the research into the mainstream competitive research environment.

It is clear to the Lead Review Team that, like other sections of the Commonwealth Department of Health and Ageing, the Population Health Division has a requirement for strategic research on which to base policy decisions and program setting. The National Centres in HIV Research have had a major role in providing the necessary research, and the infrastructure funds have been critical in maintaining the centres' capacity. But the Department also needs the capacity to influence priorities as required, and it needs the flexibility to initiate strategic research independently of the centres.

It is also clear to the Lead Review Team that monitoring and surveillance of HIV, hepatitis C, STIs and the associated risk behaviours are core public health functions. Commonwealth funding for these activities is an essential part of the national public health surveillance effort.

The Lead Review Team is strongly of the view that there is a pressing need for more research into all aspects of hepatitis C control—epidemiological, social and clinical. The lack of knowledge about fairly basic aspects of the virus's epidemiology and clinical outcomes is a serious limitation when one considers the potentially very large health care costs in the next five years.

1.2 INTRODUCTION

The Lead Review Team was charged with drawing together the reports of the review teams for HIV, hepatitis C and strategy research and the subsequent commentary on those reports by the Reference Panel, which included the current Chair of the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) and representation from the Commonwealth Department of Health and Ageing. The Team's Terms of Reference are at Section 1.9 (Appendix A).

In this report the Lead Review Team has taken the approach of synthesising the recommendations of the individual reviews, to indicate the high-level directions it considers should be taken. In this, it has also drawn on the international perspective brought to it by two of the Team members. The Team makes detailed recommendations only where these differ from those of the individual reviews and where it believes it can add value. It has not attempted to rewrite the material presented by the individual review teams.

Unless otherwise specified, the Lead Review Team endorses the recommendations of the individual reviews. It considers, however, that it is a matter for the governing committees charged with developing subsequent strategies to prioritise both its own recommendations and those arising from the individual reviews.

1.3 HIV/AIDS

1.3.1 Context

The Joint United Nation Programme on HIV/AIDS (UNAIDS) report on HIV/AIDS, prepared for the XIV International AIDS Conference in July 2002, clearly described the rapidly escalating scale and spread of the HIV epidemic in every part of the world (UNAIDS 2002).

In particular, there have been major increases in the prevalence of HIV/AIDS in Australia's neighbours Papua New Guinea and Indonesia, as well as in our regional partners Thailand and China, in the last five years. Any rational appraisal of the situation in Papua New Guinea—Australia's nearest neighbour and the largest recipient of Australian aid—would conclude that, in terms of health and economic impacts, that nation is facing a situation equivalent to what has confronted the worst-affected parts of Africa (AusAID 2002).

There is now clear evidence that, with committed political leadership, well-resourced prevention programs and widespread access to anti-retroviral treatments, HIV can be controlled and contained; examples are Uganda, Senegal and Brazil. The evidence is equally clear that, where these elements are not present, HIV can spread with remarkable speed; examples are Russia, the Ukraine and China.

Globally, the HIV epidemic is primarily a result of sexually transmitted infection among heterosexuals in populations afflicted by social disruption, poverty and powerlessness. In contrast, most cases of HIV in Australia are sexually transmitted but primarily among men who have sex with men.

The annual number of AIDS diagnoses in Australia peaked at 954 cases in 1994, dropping to 178 cases in 2001. This decline in incidence since 1994 was the result of two factors: a sharp drop in HIV incidence in the mid-1980s; and the effectiveness of combination anti-retroviral therapy in people whose HIV infection was diagnosed before they had progressed to AIDS (National Centre in HIV Epidemiology and Clinical Research 2002).

The incidence of HIV infection has been steady for several years, but there is worrying evidence of a recent increase in Victoria. Indicators of risk, such as increased rates of self-reported unprotected anal intercourse and increased rates of rectal gonorrhoea, support the potential for a re-emergence of the epidemic if there is not a renewed focus on prevention. Recognition of the role of STIs in increasing susceptibility to HIV infection as well as HIV infectiousness has led to the recognition that STI control must be a central component of HIV prevention.

1.3.2 Vulnerable groups

The proportion of heterosexually acquired infections has remained relatively stable and mainly reflects international mobility: most of the primary-contact infections among heterosexuals have occurred outside Australia. In comparison with countries with similar economies, Australia's HIV prevalence rate of less than 1 per cent among injecting drug users, women who report a history of sex work, and prison inmates is

exceptionally low. This is probably a result of the success of previous strategies in achieving a low prevalence generally in the Australian community and of the early strong support for harm-reduction strategies such as widespread availability of needle and syringe programs (NSPs).

But, although most cases of HIV infection in Australia occur among men who have sex with men, the potential for a rapid increase from the other sources of transmission is substantial. Three groups are especially vulnerable—sex workers, Indigenous Australians, and injecting drug users.

Sex workers

Sex workers, both female and male, report that there is continuing client demand for unprotected—that is, unsafe—sex and that there continues to be pressure from owners and managers of premises to provide this service. In addition, clients are often less aware of the risks of unsafe sex and client groups are not constant, so safe sex practices must constantly be reinforced. Where sex workers are operating illegally, are new to the work, have drug and/or alcohol problems, or do not speak English, there is added vulnerability. Further, the pool of sex workers is constantly changing, so education programs must be ongoing.

Because of these characteristics of the sex worker population, peer education remains a vital component of any preventive strategy. The vulnerability of street sex workers is particularly noted. The health system's capacity to engage constructively with sex workers continues to be hampered by the varying legal status of prostitution and sex premises in the different jurisdictions, and especially the law relating to street sex workers.

Indigenous Australians

Rates of HIV infection among Indigenous Australians are very similar to those in the population as a whole, although the actual numbers may be higher as a result of under-reporting of Indigenous status in surveillance data. Rates of STIs remain substantially higher in the Indigenous community than in the general population; this is an added concern because of the consequent HIV susceptibility for this community. Male homosexual contact was the most frequently reported route of HIV transmission among Indigenous people; compared with the general population, however, a higher proportion of cases of HIV infection in the Indigenous community were attributed to heterosexual contact and to injecting drug use (National Centre in HIV Epidemiology and Clinical Research 2002).

Injecting drug users

The very low prevalence of HIV infection in Australia among people who regularly inject illicit drugs is extraordinary by international standards. It reflects an early commitment in Australia to NSPs, preventing the establishment of HIV in this population. Experience elsewhere confirms, however, that the situation can change very quickly if such programs are discontinued and that, once HIV is established in this group, it is difficult to regain control. A serious threat the Lead Review Team was alerted to is the evidence of increased sharing of injecting equipment and the closure of local NSPs.

The return on the investment in prevention through NSPs is extremely good: every \$1 spent is estimated to have saved more than \$23 in treatment and care costs; and possibly more than 24 000 cases of HIV and 800 HIV deaths have been averted since 1981 (Department of Health and Ageing 2002). This is likely to be an underestimate if one takes account of the most recent (higher) estimates of life treatment costs of HIV (Applied Economics 2001).

One area of concern reported to the Lead Review Team was the growing problem of injecting drug use in rural and regional areas and the lack of NSPs, and harm-reduction services generally, for such groups. The Team is also concerned by reports of forced closures or inappropriate relocation of NSP outlets. NSP outlets can generate considerable local concern and tension when they are not well managed, and even when they are well managed, if there is lack of political will (at local and state levels) to support the services. (NSPs are discussed further in Section 1.4.)

People from culturally and linguistically diverse backgrounds

Although they do not share the same level of vulnerability to epidemic infection, people from culturally and linguistically diverse backgrounds have other vulnerabilities. Late presentation with HIV is more common in this group—a consequence of less awareness of the risks of infection and less understanding of the need to seek testing. In some ethnic groups, homosexuality or drug use lead to even greater marginalisation than in the general community. Similarly, for some, sex education is a difficult topic for religious and cultural reasons. These are important factors in planning both prevention and treatment programs for such groups.

1.3.3 Living with HIV/AIDS

Access to highly active anti-retroviral therapy, or HAART, has dramatically improved the survival of people with HIV, reducing mortality by over 70 per cent since 1997. This has changed the nature of the disease experience, to one of living with a chronic illness that requires continuing medical therapy. An estimated 12 730 people were living with HIV/AIDS in Australia in 2001 (National Centre in HIV Epidemiology and Clinical Research 2002).

The majority of people living with HIV are able to lead productive lives. Their lives and their productivity are, however, affected by the requirements of their therapy, the need for clinical supervision (often involving multiple clinicians) and the side effects of HAART. These people experience significant personal costs as a result of their medical needs—in a situation where it is estimated that 30 per cent already live below the poverty line. In addition, their mental health is challenged by the impact of living with the disease, the consequences it has on their relationships with partners and families, and threats to their livelihood caused by the disease and potential discrimination in the workplace. Moreover, a significant number, if not all, will eventually develop resistance to HAART and progress to AIDS.

1.3.4 Testing, pharmacotherapy and public health

HIV testing has played a central part in prevention and clinical management in Australia. The arrangements that have been implemented are predicated on

encouraging readily available voluntary testing (within the context of counselling and informed consent) and a legal framework designed to ensure privacy, confidentiality and non-discrimination. Successful implementation has been underpinned by securing a safer blood supply and by surveillance and epidemiological research.

Essential to this have been special efforts to ensure the validity and reliability of laboratory assaying, including the development of standard algorithms and protocols for HIV screening and confirmatory testing. This has been complemented by authorisation of a national network of reference laboratories and quality assurance and kit evaluation work undertaken by the National Reference Laboratory. The underlying partnership between the Commonwealth, the National Reference Laboratory and the Public Health Laboratory Network can teach us much that is of relevance to hepatitis C and other communicable diseases, where more widespread testing could form a significant component of any surveillance and control strategy.

Australia provides wide access to subsidised anti-retroviral therapy through the Pharmaceutical Benefits Scheme (PBS). There is growing recognition that such access to treatment is also an important component of HIV control—both through post-exposure prophylaxis and because treatment probably reduces the potential infectivity of people living with HIV. In general, access to subsidised pharmaceuticals under the PBS is restricted to Australian nationals, permanent residents, and the nationals of countries that have health care agreements with Australia. This has the potential to exclude some groups, such as non-Australian sex workers. In public health it is accepted that, because of the benefits to the broader community, it is important to maintain open access to therapy for communicable diseases.

1.3.5 The current strategy

Australia has benefited dramatically from the longstanding strategic approach based on non-partisan political support; partnership between affected communities, government at all levels, and medical, scientific and health care professionals; and the involvement of people living with HIV/AIDS in all elements of the response. It is a model for other national health initiatives.

The priorities identified in the fourth National HIV/AIDS Strategy remain current and relevant:

- ◆ an enabling environment
- ◆ HIV/AIDS-related health promotion, including disease prevention
- ◆ treatment, care and support
- ◆ research
- ◆ international assistance and cooperation.

1.3.6 Issues identified

The primary issue the Lead Review Team has identified is a sense of complacency at many levels—including the political arena, sections of health departments, the non-

HIV clinical community, and even the broader community—that control of HIV has been achieved and the epidemic is no longer a threat in Australia. To some extent this is understandable: successful prevention and treatment have reduced the visibility of risks that were so evident during the period when deaths from AIDS were common and often high-profile. Accompanying this has been a waning in commitment to specific investment in HIV and pressure for it to be treated in the same way as any other health problem in the community.

Among other major issues identified in the review reports, and separately by the Lead Review Team, are the following:

- ◆ a perceived disengagement of members of the gay community—both those who have lived through the early phases of the HIV epidemic and younger gay men
- ◆ falling rates of HIV testing—reportedly more so among younger gay men
- ◆ the increasing complexity of prevention—given the growing number of people living with HIV and the consequent increase in the prevalence of the virus, the number of sero-discordant and sero-concordant partners, and a growing number of infected people with very low viral loads
- ◆ the increasing complexity of treatment and care—given the growing number of people living with HIV, the longer term complications of therapy, and the diversity of communities affected
- ◆ an increase in the number of late HIV diagnoses, particularly among Indigenous Australians and people from culturally and linguistically diverse backgrounds
- ◆ the substantial risk of the development of rapidly spreading epidemics in vulnerable groups such as people who inject drugs illicitly and some Indigenous communities
- ◆ the increase in STIs in the broader community, among gay men, and in parts of the Indigenous community, increasing the potential for HIV transmission
- ◆ the lack of clear measures of the effectiveness of strategies
- ◆ the need for further development and refinement of surveillance approaches
- ◆ the importance of general community strategies in protecting vulnerable groups such as people with mental illness
- ◆ unclear responsibilities for promoting harm-reduction strategies
- ◆ continued isolation of HIV/AIDS from mainstream health agendas
- ◆ lack of clarity about governance roles and responsibilities
- ◆ recognition of international mobility's potential impact on risks within Australia
- ◆ clarification of Australia's international role in confronting the global epidemic and its devastating socio-economic impact.

The complexity of HIV transmission was well summarised in a report prepared for the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD) (2002):

Patterns of HIV infection are a product of the interaction of a range of factors. Among these factors are:

- ◆ *transmission risks associated with specific sexual activities*
- ◆ *the rate of sexual mixing between infected and uninfected individuals*
- ◆ *infectiousness*
- ◆ *susceptibility.*

Knowledge of the relative weighting of these factors in determining patterns of HIV transmission continues to emerge, but is by no means fully developed. Knowledge of these factors does however explain why rates of HIV infection can fall despite increases in, for instance, risk behaviours.

An historical tendency to over-assume the role of HIV risk practices alone in determining patterns of HIV transmission continues.

Effective HIV prevention activities can include appropriate intervention to reduce the effect of each of these variables, including:

- ◆ *reducing levels of sexual risk through use of condoms; avoidance of high-risk activities; or the adoption of 'risk reduction' strategies, such as 'strategic positioning' and withdrawal*
- ◆ *reducing the rate of unsafe sexual interaction between infected and uninfected individuals through negotiation of condom use on the basis of serostatus or through seeking out of seroconcordant partners*
- ◆ *reducing infectiousness through strategies which support individuals' use of treatments, including supporting side effect management and adherence*
- ◆ *reducing susceptibility through treatment of STIs.*

The Lead Review Team is supportive of specific representation for sex workers and injecting drug users in the governance structure for a fifth National HIV/AIDS Strategy because of the marginalisation of these groups from normal health consumer mechanisms.

1.3.7 Recommendations

The Lead Review Team considers that the following action needs to be taken.

1. Develop and resource a fifth National HIV/AIDS Strategy that will:
 - ◆ include a major prevention education program focusing on men who have sex with men—as the continuing highest-risk group—targeting high-risk environments (such as ‘sex-on-premises’ venues) and hard-to-reach groups (for example, men who have sex with men but do not identify with the gay community) and being guided by epidemiological and social research data
 - ◆ be a component of a national prevention and education program promoting safe sex to the general community—that is, a program aimed at preventing STIs
 - ◆ have a greater focus on the complex and diverse needs of people living with HIV—including their mental and social health
 - ◆ following a review of the testing guidelines, promote regular HIV testing among at-risk groups, with the aim of reducing the number of people with undiagnosed HIV
 - ◆ provide support for targeted approaches such as peer education for hard-to-reach vulnerable populations—for example, sex workers and injecting drug users
 - ◆ take account of the specific needs of groups from culturally and linguistically diverse backgrounds
 - ◆ incorporate an integrated evaluation framework
 - ◆ incorporate the principles and targets of obligations arising from UNGASS—the UN General Assembly Special Session on HIV/AIDS.

The Lead Review Team recommends that planning for a fifth national strategy begin on acceptance of this report, with the aim of the strategy coming into operation by mid-2003.

2. Undertake an assessment of the growing care needs (including the mental health care needs) of people living with HIV/AIDS, to identify current barriers to effective and efficient care and the health sector’s capacity to respond to likely future demand.
3. Support a re-evaluation by the key community partner organisations—gay, injecting drug user, and sex worker organisations—of their constituencies, roles and priorities, particularly in relation to prevention of HIV and STIs and the care of people living with HIV/AIDS, with the intention of re-invigorating constituency involvement in programs of support and prevention.
4. Development of a whole-of-government policy on Australia’s role and responsibilities in relation to the international HIV epidemic (see also Section 1.7).
5. Review and implement other recommendations of the HIV Strategy Review Team, consistent with the recommendations of the Lead Review Team.

1.4 HEPATITIS C

1.4.1 Context

Hepatitis C is now the most commonly notified communicable disease in Australia. The epidemic in Australia is epidemiologically similar to the epidemics occurring in the United States, Canada and the United Kingdom. The increasing rates of infection reflect the increasing levels of injecting drug use. Although a specific laboratory test for hepatitis C has been available only since early 1990, it is clear that the epidemic was well established among injecting drug users before HIV came to prominence and had probably been affecting large numbers of people since the late 1960s.

Hepatitis C poses a serious threat to population health because acute infection can progress to chronic active hepatitis and, for some, to cirrhosis and liver failure (and possibly liver cancer). There are still major gaps in our knowledge of the early phases of infection, but most people infected with the virus probably do not eliminate it for several years. Among those who fail to eliminate the virus, the disease's progress varies, although in transfusion-associated cases probably at least one in five go on to develop cirrhosis after an average of 15–20 years. Acute, or early, infection is not usually associated with recognised illness, so individuals may not even know they are infected until tested. A further complication in controlling the epidemic is that previous infection with one strain of the virus does not protect against re-infection with the same or a different strain.

The number of notified diagnoses of newly acquired hepatitis C infections in Australia continued to increase. In 2001 almost 600 cases were identified, and these represent only a small fraction of the 16 000 cases estimated to have occurred in Australia in 2001. An estimated 210 000 people living in Australia in 2001 had been exposed to the virus. Of these, an estimated 53 000 had cleared their infection and were not chronically infected, 124 000 had chronic hepatitis C infection and early liver disease (stage 0/1), 27 000 had chronic hepatitis C infection and moderate liver disease (stage 2/3), and 6500 were living with hepatitis C-related cirrhosis (National Centre in HIV Epidemiology and Clinical Research 2002). It is estimated that by 2020 as many as 500 000 people in Australia will be infected with hepatitis C (Hepatitis C Virus Projections Working Group 2002).

1.4.2 Prevention beyond needle and syringe programs

Over 90 per cent of new hepatitis C infections in Australia occur in the context of injecting drug use. As a consequence, this has to be the main target of any strategy to prevent infection and stop the epidemic. Wide availability of and easy access to clean needles and syringes must remain a cornerstone of any strategy to tackle blood-borne viruses. But this is not enough. Many injecting drug users are injecting in unclean, uncontrolled environments—in laneways, for example—without easy access to hand-washing facilities. Equipment other than the needles and syringes (such as tourniquets and spoons) may be shared; further, some users have difficulty finding a vein, and there can be substantial blood contamination in their immediate vicinity.

From the perspective of health promotion and education, people who use illicit drugs are not a group that is easily reached. Their contact with health services is often brief

(for example, when collecting clean syringes) or occurs in situations that are not amenable to education (for example, after an overdose). Not unreasonably, they are suspicious of authority, and they may not relate socially and culturally to the usual health care worker. As a result, interventions have to be brief and focused. Many NSP workers have limited understanding of the culture of injecting drugs; most of them have little training. Training programs have been developed to improve the primary care skills of NSP workers, including their skills in brief intervention and in facilitating referral of users to appropriate services. Another strategy applicable to marginal and hard-to-reach groups is peer education, and it has an important place in this setting.

Harm reduction involves more than the provision of clean needles and syringes. It also incorporates dependency-treatment services and demand reduction. The full range of approaches—including alternatives to injection—should be considered in the context of reducing the possibility of transmission.

Prisons are one of the most important fuelling stations for the hepatitis C epidemic in Australia. In contrast with HIV, a very high proportion of people entering prison already have hepatitis C. Despite the efforts of custodial staff to reduce the influx of drugs, there continues to be high levels of injecting drug use in prisons. Tattooing and body piercing is common among prisoners frequently by untrained operators with poorly sterilised equipment (if at all) and is well documented as a source of transmission. Prison populations are surprisingly mobile: prisoners are moved between locations to help balance prisoner numbers, to meet special needs such as that for protection, and for access to court. There is also a very large flow of prisoners into and out of prisons. Among health care workers who work with prisoners, the difficulty of maintaining care between prison and the community is well recognised. This has implications for drug-dependency treatment, for harm minimisation, and for treatment of conditions such as hepatitis C.

1.4.3 Other sources of infection

Three other sources of hepatitis C infection are important. First, there is a small group of people who acquired the infection through contaminated blood products; this source has rapidly declined in importance as new-generation testing procedures have been introduced. Second, there are cases among established migrants, who probably became infected through exposure to poor medical practices prior to migration; this group may not contribute substantially to growth in the epidemic but, because of difficulties with identification and access, should be recognised in any future strategy. Third, there is an unknown proportion of cases associated with poor tattooing and body-piercing practices; this group is probably fairly small, too, but it could become important if changes to legislation inadvertently encouraged younger people to undergo tattooing or body piercing in unhygienic conditions—for example, by non-professional operators and peer-group members.

1.4.4 The treatment dilemma

As noted in Section 1.4.1, it is estimated that a substantial proportion of cases of hepatitis C infection go undiagnosed and untreated. The New South Wales Anti-Discrimination Board's report of its enquiry into hepatitis C-related discrimination documents a high level of ignorance about the disease in the community and among health professionals. The impact of being identified as carrying the hepatitis C virus (or HIV), particularly if the infection was acquired through injecting drug use, can be devastating. It can lead to discrimination in employment, access to insurance and health care. In such an environment, it is not surprising that many people who think they might be infected decide they would rather not know.

It is unlikely that a vaccine against hepatitis C will be available in the near future. Therapies are improving: 'cure' rates are approaching 50 per cent in subgroups but are associated with considerable side effects during treatment. Although early data support the contention that 'cure' means the virus is no longer active and long-term liver damage has been prevented, this remains to be confirmed by longer term follow-up studies. It is estimated that 7 per cent of infected people in Australia receive treatment at present. Rates of treatment uptake are reportedly higher in some countries—for example, in Italy, where the rate is closer to 20 per cent.

Current treatment itself entails substantial morbidity. To obtain pharmaceutical treatment once diagnosed, a person must have a liver biopsy, which is not only a rate-limiting step but is also associated with significant risks. Among the available pharmaceutical treatments is interferon, which is given two to three times a week and causes a flu-like illness. Considering that a person's infection may have been symptomless and that the benefits of interferon become apparent only in the long term, this can deter some people from seeking treatment.

Unless prevention becomes more effective, hepatitis C has major implications for future health care costs. Estimation of the future impact of the disease and of the nature of effective control programs is severely hampered by the limitations of the available epidemiological, social and clinical research. However, the indications are that, without adequate investment in prevention now, the annual health care costs of the disease could grow into hundreds of millions of dollars.

1.4.5 The current strategy

Australia's National Hepatitis C Strategy 1999–2000 to 2003–04 was an international first and is to be commended. But the available evidence suggests that the strategy has made little or no progress in controlling the epidemic. The essential components of the strategy, modelled on the successive HIV strategies, are developing partnerships and involving affected communities, access and equity, harm reduction, health promotion, research, surveillance, and linked strategies and infrastructure. As detailed by the Hepatitis C Strategy Review Team, there is substantial room for improvement in every one of these components. That team's review indicates that at least some of those components have been under-resourced when the size of the problem is taken into consideration.

Moreover, the current strategy inadequately recognises that there is a very large infected but undiagnosed population that continues to fuel the epidemic. Until the size

of this pool is reduced, it will be difficult to make progress. There appear to be substantial barriers to wider access to treatment—although treatment could play an important part in controlling the epidemic by reducing the infective pool.

1.4.6 Issues identified

Among the primary issues identified by the Hepatitis C Strategy Review Team, and separately by the Lead Review Team, are the following:

- ◆ variable recognition, at all levels of the health system, of the growing impact of hepatitis C and its probable future health care costs
- ◆ lack of understanding of the social and environmental settings in which injecting drug use occurs and the implications of this for prevention
- ◆ failure to fully appreciate the various factors associated with reducing transmission—other than the supply of clean needles and syringes
- ◆ continuing, if not growing, discrimination in the health care system and in the workplace against people with hepatitis C—particularly where infection is perceived to be linked to past or current injecting drug use
- ◆ inadequate involvement in and ownership of the strategy by the main risk group—injecting drug users
- ◆ inadequate attention in the National Drug Strategy to broader health concerns for injecting drug users—particularly control of hepatitis C
- ◆ inadequate attention to the role of prisons in fuelling the epidemic and to the special requirements for delivering health care to prison populations
- ◆ inadequate surveillance information on rates and the characteristics of new infections
- ◆ major gaps in knowledge of ongoing infectivity and the rate and implications of viral clearance
- ◆ inadequate information about risks associated with infection sources other than injecting drug use—particularly for body piercing and tattooing
- ◆ a greater need to specifically champion hepatitis C as a serious public health concern in its own right
- ◆ the inadequate response of health care professionals in terms of recognising the broader benefits of testing for and treating hepatitis C
- ◆ the limitations of available treatments
- ◆ problems with access to existing health care services—particularly in rural and regional areas—and the need for models of care that are more innovative and responsive

- ◆ increasing community resistance to the maintenance and expansion of harm-reduction strategies such as NSPs
- ◆ drug treatment services' lack of responsiveness to the broader health care needs of people infected with hepatitis C and particularly the potential public health benefits of treating the disease.

1.4.7 Recommendations

The Lead Review Team considers that the following action needs to be taken.

6. Clearer identification and championing of hepatitis C as an urgent national public health problem by the medical and public health community.
7. Develop and resource an improved second National Hepatitis C Strategy, drawing on the findings of this first review, to be in effect by mid-2003.
8. In recognition of the potential future health care costs posed by hepatitis C, commensurately increase investment in efforts to prevent the spread of the virus.
9. Implement a program to improve and expand current harm-reduction strategies, including:
 - ◆ implementing best-practice models for NSPs—involving training of NSP workers, better referral systems, and proactive local management systems to allay community concerns
 - ◆ increasing the availability of medical detoxification—with particular attention to accessibility outside metropolitan areas
 - ◆ improving access to substitution therapies such as methadone and buprenorphine
 - ◆ investigation of other approaches to reducing injecting as the preferred method of drug delivery.
10. Develop and implement specific programs for preventing the spread of and for treating blood-borne viruses in prisons. This needs to include more effective harm reduction in prisons and improved coordination of prevention and care services between prison and the community, as is currently being strived for in drug-dependency services.
11. Uniformly regulate the body-piercing and tattooing industries—to ensure that these industries do not become a growing source of infection while not being so prohibitive that young people are forced into unsafe practices.
12. Resource a specific research program dealing with the issues that will inform policy and practice—including the epidemiological, social and cultural aspects of risks and transmission and the barriers to seeking treatment.
13. Develop and implement improved surveillance methods for hepatitis C.

14. Implement a process to review the national implications of the findings of the New South Wales Anti-Discrimination Board's 2001 enquiry into hepatitis C-related discrimination.
15. Ensure greater involvement of at-risk groups in strategy planning and implementation—with particular attention to the use of peer-group education.
16. Ensure greater engagement on the part of the Intergovernmental Committee on Drugs and drug-dependency services in matters associated with the physical health of injecting drug users—including greater commitment to controlling the spread of hepatitis C.
17. Review and implement other specific recommendations of the Hepatitis C Strategy Review Team, consistent with the recommendations of the Lead Review Team.

1.5 RESEARCH

1.5.1 Context

All aspects of Australian HIV research—social, epidemiological, clinical and virological—have earned international recognition.

Compared with HIV research, hepatitis C research is lagging behind, both quantitatively and qualitatively, in all areas, although there are some examples of high-quality endeavours. The situation is probably similar in other comparable countries but, as with HIV, there is an opportunity for Australia to show leadership.

The 1999 Strategic Review of Health and Medical Research has guided recent developments in government policy relating to investment in health research. Some of the key issues identified by that review are:

- ◆ recognition of the differing needs of priority-driven research and investigator-initiated research
- ◆ a strong emphasis on contestability for funding of investigator-initiated research
- ◆ support for the development of critical masses of researchers through networking and aggregation
- ◆ the need to support longer term research initiatives.

In responding to that review, the Commonwealth Government has indicated its commitment to contestability and made this a requirement for the large increase in funding for health research. The National Health and Medical Research Council (NHMRC) has introduced a number of new initiatives—examples are an increase in the number of large five-year program grants, industry-linkage grants, public health capacity-building grants, and the recently announced Wellcome Trust – NHRMC program grants in tropical disease research. These principles and opportunities need to be considered in any future decisions about specific funding for hepatitis C and HIV.

1.5.2 The current situation

The funding of the national centres in HIV epidemiology, social and behavioural, viral, and clinical research has provided a solid research capacity, as confirmed by the individual reviews of the centres. It has enabled the development of internationally competitive research groups.

1.5.3 Issues identified

The primary issues identified in the report of the Strategic Research Review Panel, and separately by the Lead Review Team, are as follows:

- ◆ the role of the Population Health Division of the Commonwealth Department of Health and Ageing in funding research
- ◆ concerns in the community about priority setting for research

- ◆ a perceived lack of response to regional research needs and specific populations
- ◆ tensions in the research agenda between strategic research (research arising from and directly informing the directions of policy and practice) and investigator-initiated research normally funded through competitive mechanisms
- ◆ a perceived lack of responsiveness on the part of the NHMRC and the Australian Research Council to strategic research needs, particularly in social health, and to community priorities
- ◆ concern that, without specific-purpose funding, there will not be the necessary research effort, that the effort will become too diffuse, and that expertise will be lost overseas
- ◆ perceptions in the broader medical and social research communities that the quality of HIV research funded through the specific funding to the national centres is not of the quality that could be achieved through open competition
- ◆ the vital role of surveillance and monitoring, with the need for specific research into new methods of surveillance
- ◆ the tighter funding environment for strategic research.

In the Lead Review Team's opinion, at this stage the continuing success of the national centres is not threatened by a close examination of the alignment of the centres' current activity and resourcing with strategic research needs.

It is clear to the Lead Review Team that, like other sections of the Department of Health and Ageing, the Population Health Division has a requirement for strategic research on which to base policy decisions and program setting. It is also clear to the Team that monitoring and surveillance of HIV, hepatitis C and STIs and the associated risk behaviours are core public health functions. Commonwealth funding for these activities is an essential part of the national public health surveillance effort.

The Lead Review Team does not consider that the Population Health Division has a principal role in funding investigator-initiated research, except where that research is aligned with the division's strategic research needs. It is more appropriate for the NHMRC and the Australian Research Council to handle this type of research.

The Lead Review Team agrees with the Strategic Research Review Panel that there is a need to maintain the capacity of the National Centre in HIV Epidemiology and Clinical Research. The work funded by the Population Health Division is undoubtedly either core public health business or strategic research.

The Lead Review Team also agrees with the Strategic Research Review Panel that there is a need to maintain the capacity of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society. There are, however, concerns about the perception that the centres have not adequately dealt with needs in some regions and some populations and that they have not adequately discharged their role of fostering capacity outside the centres. This needs to be promptly redressed by the centres.

If the Lead Review Team's view on the priorities in the Population Health Division's research funding is accepted, the Department should review its funding commitment to the National Centre in HIV Virology Research to ensure that the funding is consistent with the centre's core business of surveillance and monitoring or the Department's strategic research needs.

Further, the Lead Review Team considers that there is a strong case for additional investment in research into all aspects of hepatitis C. As well as reviewing the distribution of the current funds, consideration should be given to hepatitis C research forming a core component of the research investment under the National Drug Strategy. An appropriate mechanism would be an NHMRC program grant in hepatitis C research jointly funded by the NHMRC and the Department.

It is the Lead Review Team's view that there should be no constraints on the national centres applying for competitive NHMRC and Australian Research Council funds for HIV and hepatitis C research—other than where the work is identified as part of their contractual monitoring, surveillance and strategic research obligations.

A mechanism for developing and coordinating advice on research priorities across HIV, hepatitis C and STIs is needed. The Lead Review Team recommends that a strategic research advisory committee for HIV, hepatitis C and STIs continue to operate, under the auspices of and supported by the Population Health Division. The committee should have an external chair with research expertise, and it should have representation from the hepatitis C, HIV and Indigenous Australians' sexual health committees, the NHMRC and the Communicable Diseases Network Australia.

1.5.4 Recommendations

The Lead Review Team considers that the following action needs to be taken.

- | | |
|-----|---|
| 18. | Review the contracts between the Commonwealth Department of Health and Ageing and the National Centres in HIV Research, to specify as clearly as possible the elements of funding for surveillance and monitoring and for strategic research. |
| 19. | For the Population Health Division, convene, at least yearly, round tables of stakeholders, to identify and set priorities for strategic research. |
| 20. | Within two years, carry out an assessment of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society to ensure that the concerns about the reach of their research programs are addressed. |
| 21. | Begin negotiations to identify funding for and a process for establishing a research program for hepatitis C. |
| 22. | Monitor the funding transition process to ensure that relevant strategic research is not interrupted. |
| 23. | Review and implement all specific recommendations of the Strategic Research Review Panel, consistent with the recommendations of the Lead Review Team. |

1.6 LEADERSHIP AND GOVERNANCE

The Lead Review Team acknowledges the importance of ANCAHRD in providing high-profile leadership relevant to HIV and hepatitis C under the third and fourth National HIV/AIDS Strategies. ANCAHRD has:

- ◆ provided a single point of reference that has been particularly important for overlap issues, such as supporting the need for harm-reduction strategies and non-discrimination
- ◆ enabled coordination of efforts
- ◆ established a high profile, both in the community and politically
- ◆ provided an arm's length vehicle for endorsement of specific campaigns
- ◆ fostered the development of the Indigenous Australians' Sexual Health Strategy
- ◆ sought to engage with the states and territories and with regional stakeholder communities.

The Lead Review Team also acknowledges concerns that any change to governance arrangements should not result in losing these benefits. Nevertheless, there are simultaneously concerns about the following:

- ◆ the lack of clarity in relation to the executive versus advisory roles of ANCAHRD
- ◆ deflection of government responsibility for leadership
- ◆ a perceived lack of responsiveness to the needs of interest groups
- ◆ the degree to which synergies between HIV and hepatitis C can be achieved
- ◆ structural barriers to better articulation of hepatitis C-related matters within the National Drug Strategy
- ◆ the potential political unacceptability of a stand-alone hepatitis C strategy because the epidemic is so strongly associated with injecting drug use
- ◆ the lack of a clear remit to deal with the broader question of STIs in the community.

There was a strongly expressed view that the Commonwealth needs to re-establish its leadership role more directly and through parliamentary liaison processes. International experience confirms the importance of political leadership in containing epidemics.

Among other aspects of leadership that were canvassed are the need to re-invigorate the leadership roles of non-government organisations, clinicians, and the states and territories. Additionally, there was concern that the funding seen as principally for the HIV/AIDS Strategy was being diverted to the Hepatitis C Strategy: this concern arose partly from disquiet about the transparency of the decision-making process.

The Lead Review Team also considered whether the governance arrangements should reflect an approach based more on risk behaviours (principally sexual risk behaviours and risk behaviours associated with skin penetration), rather than the current disease-based approach. The strongest argument in favour of the former is that it more clearly aligns with the preventive strategies. On the other hand, the current approach is now well established, is probably more acceptable publicly, and recognises that the strategies cannot be about prevention alone. On balance, the Team decided that the disease-based model remains the preferred option.

The Team considered the following options for governance arrangements:

- A. continuation of ANCAHRD in its current form
- B. the model proposed by the hepatitis C and HIV reviews, involving four separate committees—Hepatitis C, HIV, Indigenous Australians’ Sexual Health, and Legal Working Party—with or without a coordinating committee made up of the chairs and deputy chairs of those separate committees
- C. a model that would expand the role of ANCAHRD
- D. a model limited to two separate committees—Hepatitis C and HIV—with joint working parties on overlap matters such as harm reduction, research priorities, legal issues and Indigenous Australians’ health
- E. a model based on the National Health Priorities framework, with hepatitis C and HIV and STIs as separate priorities
- F. variations on models B and E but with an overarching coordinating committee with a well-defined role limited to promoting overlap matters.

In weighing up the options, the Team was influenced by the following considerations:

- ◆ the need to lift the profile of hepatitis C and STIs as serious national health problems
- ◆ the need to be clear about who has responsibility for funding decisions and about the balance of investment in HIV and hepatitis C
- ◆ the need to better recognise the complex care and treatment requirements of people with HIV or hepatitis C—which overlap with the problems of other chronic diseases
- ◆ the benefits of consistency with approaches to other national health problems—including a recognition that such problems require a ‘whole of department’ response rather than a response from the Population Health Division alone
- ◆ the need to signal that HIV and hepatitis C will remain national health problems for the foreseeable future
- ◆ the undesirability of multiple committees with overlapping responsibilities.

On balance, the Lead Review Team favours a governance model that better identifies the separate strategies for hepatitis C (and other viral hepatitis) and HIV – STIs. The Team also considers it important to signal the need for a better ‘whole of health

sector' response and to more clearly identify the two strategies with mainstream health care.

Recommendation 24

It is thus recommended that, as the principal point of governance, each strategy have a governing committee appointed by the Minister for Health and Ageing. Membership of each committee should represent all members of the partnership, but must include the following:

- ◆ relevant specialist medical expertise
- ◆ general practice
- ◆ the non-government partners
- ◆ the Indigenous community
- ◆ public health expertise
- ◆ health promotion, research and evaluation expertise.

Given some of the new direction that is needed in campaigns, it is particularly important that expertise in health promotion and research and evaluation is included.

This approach offers a number of advantages:

- ◆ separate but equal governance arrangements for hepatitis C and HIV
- ◆ specific recognition of the broader question of STIs and their commonalities with HIV
- ◆ consistency with other whole-of-department approaches such as the National Health Priority Areas
- ◆ better recognition of the complex care and treatment needs of people with hepatitis C or HIV
- ◆ better recognition of the full cost implications of care and treatment for both epidemics
- ◆ maintenance of an arm's length arrangement for endorsement of specific campaigns and programs.

Figure 1.1 shows the proposed new governance structure.

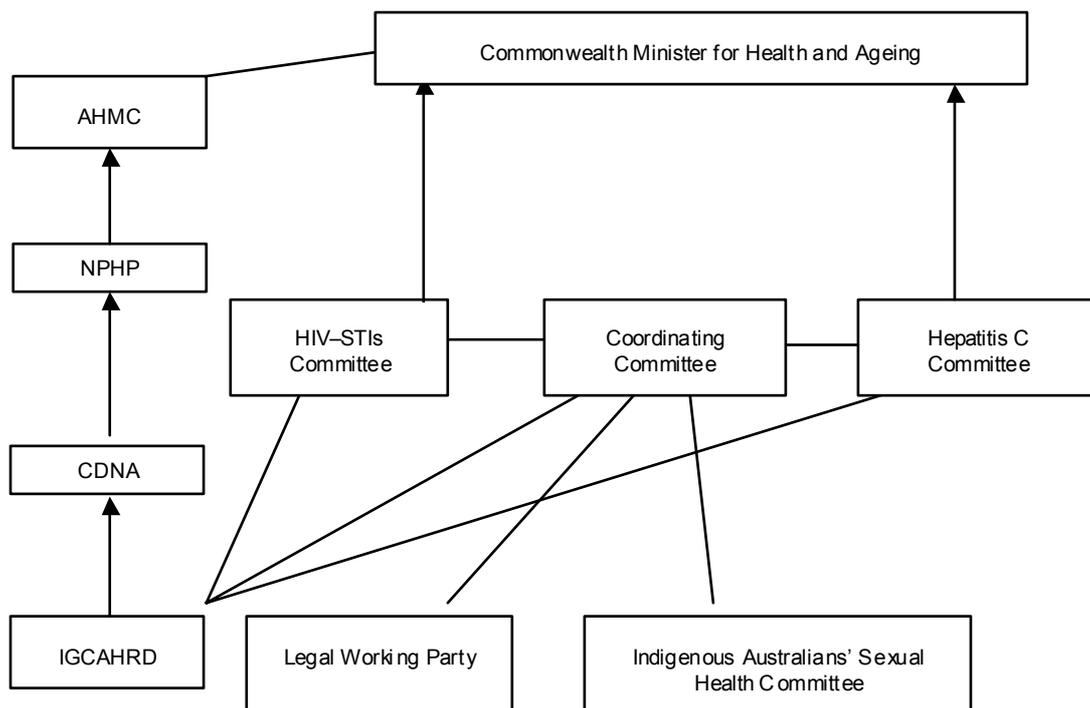


Figure 1.1 Proposed governance structure for hepatitis C, HIV and STIs

These committees—particularly the Hepatitis C Committee—would be well served by chairs who can champion their cause with the independence, acumen and commitment shown by the current chair of ANCAHRD.

Although the Lead Review Team considers that there is need to lift the profile of the separate strategies, it is also mindful that much has been achieved through the existing single-committee approach. In particular, there are overlap areas—such as legal matters and harm reduction—where a joint approach is arguably both appropriate and more efficient.

Harm reduction remains a cornerstone of the National Drug Strategy and is broadly accepted across government. The Lead Review Team is concerned by the lack of clarity in responsibility for monitoring, development and promotion of communicable disease-prevention components such as NSPs.

Recommendation 25

The Team considers that a joint coordinating committee would be appropriate, with responsibility for legal matters and harm reduction. If this model is accepted, such a committee's Terms of Reference should make it clear that it does not have executive decision-making powers in relation to the individual budgets for HIV-STIs or hepatitis C. Its membership should include the chairs of the HIV-STIs, Hepatitis C and IGCAHRD Committees and representation from the Australian National Council on Drugs (ANCD).

Whatever model is adopted, it is essential that there be clear identification of separate budgets for HIV–STIs and hepatitis C, clear definition of the decision-making powers of the governing committees and their chairs, and transparency and accountability to partner organisations.

Recommendation 26

The Lead Review Team considers that the specific concerns of Aboriginal and Torres Strait Islander peoples warrant the continuation of a separate committee for the Indigenous Australians' Sexual Health Strategy. Moreover, since this strategy has set out to achieve a holistic approach to STIs, HIV and hepatitis C—in keeping with the philosophy of broader Indigenous health—it is appropriate that the chair of the committee be a member of the coordinating committee.

Stakeholders repeatedly praised the work of the Legal Working Party and expressed support for its continuation.

Recommendation 27

In the Team's view, the Legal Working Party should continue to provide support to both strategies and therefore is most appropriately represented through the coordinating committee.

It is also essential that there continue to be a group to coordinate policy and practice across the states and territories and the Commonwealth: IGCAHRD remains relevant in this context. The Team notes concerns that IGCAHRD had been less influential since it took its position under the National Public Health Partnership network. It appears, however, that this was probably related in part to the level of representation on IGCAHRD, and the Team notes the improvement in the quality of work under the new chair.

The Lead Review Team also considered the question of accountability and reporting arrangements for Commonwealth-funded programs. There was a strong view, particularly from the community sector, that there was a need for greater accountability. Overall, the Lead Review Team agrees with the HIV/AIDS Strategy Review Team that the question was more about how the overall level of the response to both HIV/AIDS and hepatitis C could be monitored, rather than about specific accountabilities. The Lead Review Team supports the approach suggested by the HIV/AIDS Strategy Review Team—to conduct a regular survey of activity, separately from the reporting requirements of specific intergovernment agreements.

1.7 INTERNATIONAL ENGAGEMENT

The social and health consequences of the global HIV epidemic are well established, particularly in Africa and parts of Southeast Asia. The economic (and population) impacts are now raising fears for international security because of the epidemic's potential to politically destabilise regions, including Southeast Asia.

Australia has maintained a special relationship with its nearest neighbour, Papua New Guinea. Because Papua New Guinea is the largest recipient of Australian aid funds and because of its proximity to Australia, the escalation of the HIV epidemic in that country must be a particular concern.

Australian expertise in a number of areas can contribute to international efforts to control HIV—community engagement; surveillance; blood and blood-product safety; virology; social, epidemiological and vaccine research; all aspects of harm reduction; and strategies for working with groups such as sex workers and injecting drug users.

Australia has taken an important leadership role in pressing for an international response to HIV and had a major role in the development of the UNGASS agreement, to which it is a signatory.

Recommendation 28

The size and impact of the global HIV epidemic are such that the Lead Review Team considers there is a need for a whole-of-government international policy on Australia's role in tackling the problem. Such a policy would specify the following:

- ◆ how Australia's reporting obligations under the UNGASS agreement will be met and who will coordinate the process
- ◆ funding priorities for aid
- ◆ development and maintenance of a human resource base to support international efforts
- ◆ development of a system to ensure better integration of Australia's research and project capacity with international efforts, particularly with regard to vaccine and microbicide development and trialling
- ◆ development of a position on funding of and access to affordable HIV therapy in developing countries
- ◆ development within the Asia-Pacific region of inter-country agreements on treatment and prevention programs for STIs.

Development of this policy should be a joint responsibility of the Department of Health and Ageing, the Department of Foreign Affairs and Trade, and AusAID (the Australian Agency for International Development)—possibly under the chairmanship of the Chief Health Officer. The policy should guide Australia's international assistance program and would promote the continuing involvement of the Ministerial HIV Committee in international activity.

1.8 CONCLUDING REMARKS

Australia has been well served by its past and current HIV/AIDS and hepatitis C strategies and the accompanying research effort. In formulating its recommendations, the Lead Review Team has strived to ensure that any suggested changes would not detract from the strengths of previous strategies. However, the epidemiological, social and clinical context for both HIV/AIDS and hepatitis C is changing, as is the broader social and political environment, and this needs to be taken into account. Health systems' responses to many health problems have been influenced by the success of the response to HIV/AIDS. During the period of the HIV epidemic there have been enormous changes in the way health care more broadly is provided. Our HIV/AIDS and Hepatitis C Strategies need regular review if they are to remain current and at the forefront of change.

The Lead Review Team specifically acknowledges the work of the individual research and strategy review teams; their reports form the basis of this report. The Team found very few examples of matters the individual reviews had not already dealt with and, in the case of the recommendations, any differences are primarily a matter of focus, pragmatism or opinion.

The Lead Review Team also thanks the Reference Panel, which provided frank and sometimes challenging feedback that was absolutely essential.

Finally, the Team acknowledges the excellent and expert support provided by departmental staff; they made our task enjoyable and substantially easier.

1.9 APPENDIX A LEAD REVIEW TEAM TERMS OF REFERENCE

Following are the Lead Review Team's Terms of Reference, as issued by the Department of Health and Ageing in July 2002.

The Lead Review Team will provide advice to the Commonwealth Minister for Health and Ageing in order to inform the next phase of Australia's public health response to the HIV/AIDS and hepatitis C epidemics, including their relationship to other communicable diseases and broader sexual health issues.

The Lead Review Team will be broadly guided by the specific areas of priority as outlined in the Terms of Reference of the National Strategies and Strategic Research Review Teams as per attachment A.

The critical task for the Lead Review Team will be to compile the final report on the outcomes of the reviews, including broad priorities and recommendations as to future directions for HIV/AIDS and hepatitis C. In doing so, the Lead Review Team will incorporate the recommendations of the National Strategies and Strategic Research Review Teams and consider input provided by the Reference Panel.

Attachment A

Terms of Reference—Review of the National HIV/AIDS Strategy

The review will provide advice to the Commonwealth Minister for Health and Ageing in order to inform the next phase of Australia's public health response to the HIV/AIDS epidemic, including its relationship to other communicable diseases and broader sexual health issues. The Review will:

1. Assess the extent to which the current National HIV/AIDS Strategy has been effective, having particular regard to
 - ◆ the Strategy's position in a broader communicable diseases context;
 - ◆ the degree to which it has been implemented;
 - ◆ the achievement of Strategy objectives listed under the following five priority areas:
 - the creation of an enabling environment;
 - HIV/AIDS related health promotion, including disease prevention;
 - treatment, care and support;
 - research; and
 - international assistance and cooperation.
 - ◆ the priority health needs of Aboriginal people and Torres Strait Islanders.
2. Assess the appropriateness, strength and effectiveness of the *partnership* in representing and progressing responses to HIV/AIDS through an analysis of the roles, responsibilities and activities of

- ◆ the Commonwealth Government, State and Territory governments, and local government;
 - ◆ the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD);
 - ◆ research, medical, scientific and health care professionals;
 - ◆ the Non-Government Organisation and community sectors.
3. Examine the transferability of approaches, partnerships, principles and services in HIV/AIDS to other chronic diseases.
 4. Examine the impact of HIV/AIDS in the Asia-Pacific region, analysing the role Australia might play in providing assistance, and identifying which bodies might most appropriately implement Australia's role.
 5. Identify and analyse strategic links with other National Strategies, including the National Hepatitis C Strategy 1999–2000 to 2003–04, the National Indigenous Australians' Sexual Health Strategy 1996–97 to 1998–99 (as extended) and the National Drug Strategic Framework 1998–99 to 2002–03, having regard to the quality, strength and extent of those links.
 6. Identify any:
 - ◆ new or shifting priorities; and/or
 - ◆ gaps in implementation; and/or
 - ◆ barriers to achieving sustained control of HIV in Australia, which might reshape the strategic response to HIV/AIDS and inform the next phase of Australia's public health response to the HIV/AIDS epidemic and other related communicable diseases

Terms of Reference—Review of the National Hepatitis C Strategy

The Review will provide advice to the Commonwealth Minister for Health and Ageing in order to inform the next phase of Australia's public health response to the hepatitis C epidemic, including its relationship to other communicable diseases. The Review will:

1. Assess the extent to which the National Strategy has been effective, having regard to:
 - ◆ the strategy's position in a broader communicable diseases context;
 - ◆ the degree to which it has been implemented;
 - ◆ the achievement of the Strategy's objectives listed under the following essential components of Australia's response:
 - developing partnerships and involving affected communities;
 - access and equity;
 - harm reduction;
 - health promotion;

- research;
 - surveillance; and
 - linked strategies and infrastructures.
- ◆ the priority health needs of the Aboriginal people and Torres Strait Islanders.
2. Assess the appropriateness, strength and effectiveness of the *partnership* in representing and progressing responses to hepatitis C through an analysis of the roles, responsibilities and activities of
- ◆ the Commonwealth Government, State and Territory governments, and local government;
 - ◆ the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD);
 - ◆ research, medical, scientific and health care professionals; and
 - ◆ the Non-Government Organisation and community sector.
3. Assess the:
- ◆ clinical outcomes for hepatitis C;
 - ◆ social and behavioural factors related to the transmission of hepatitis C;
 - ◆ uptake of treatments by people living with hepatitis C;
 - ◆ social, economic and personal impacts of new hepatitis C treatments; and
 - ◆ impact of hepatitis C-related social issues such as discrimination, stigma, and maintenance care and support.
4. Assess the extent to which the National Strategy has achieved its primary aims in the specific areas of rural and regional services, and custodial settings.
5. Assess the appropriateness and effectiveness of hepatitis C surveillance mechanisms.
6. Assess the economic impact of hepatitis C, including cost to the community, Government expenditure on hepatitis C, and identification of barriers to assessing the economic impact.
7. Identify and analyse strategic links with other National Strategies, including the National HIV/AIDS Strategy 1999–2000 to 2003–2004, the National Indigenous Australians’ Sexual Health Strategy 1996–97 to 1998–99 (as extended) and the National Drug Strategic Framework 1998–99 to 2002–03, having regard to the quality, strength and extent of those links.
8. Examine the transferability of approaches, partnerships, principles and services in hepatitis C to other chronic diseases.
9. Examine the impact of hepatitis C in the Asia-Pacific region and the need for international assistance and cooperation in respect of hepatitis C.

10. Identify any:

- ◆ new or shifting priorities; and/or
- ◆ gaps in implementation; and/or
- ◆ barriers to achieving sustained control of hepatitis C in Australia which might shape the strategic response to hepatitis C and inform the next phases of Australia's public health response to the hepatitis C epidemic and other related communicable diseases.

Terms of Reference—Strategic Research Review Panel

In the context of assessing the scientific quality and international competitiveness of research, the Strategic Research Review Panel will review and make recommendations on:

Scientific quality and competitiveness

1. the performance of each Centre in meeting its objectives as defined under the guiding principles and priorities of the current National HIV/AIDS, National Hepatitis C and National Indigenous Australians' Sexual Health Strategies, and in terms of the quality and international competitiveness of its research effort.
2. the progress on the recommendations from the 1997 review of the National Centres in HIV Research.

Funding arrangements

3. the appropriateness, efficiency and cost effectiveness of funding the Centres under the existing 5 year Commonwealth AIDS Research Grant (CARG) arrangements;
4. future responsibilities and operational requirements of the Centres including:
 - ◆ possible changes to their role and function, both individually and as a group.
 - ◆ the value of funding the Centres to produce quality research outcomes in line with established research priorities (i.e. those established by the National HIV/AIDS and Hepatitis C Strategies and ANCAHRD) as compared with alternative funding mechanisms, such as a competitive grants program (including the NHMRC grants program) and/or alternative research bodies.
 - ◆ the manner in which the current National Centres that were established and funded as HIV Centres have contributed, and can contribute in the future to, hepatitis C research.
5. future systems for supporting Strategy research in HIV, hepatitis C and related diseases, including:
 - ◆ systems for defining Strategy research.
 - ◆ systems for funding Strategy research (ie competitive application, contracting and/or commissioning).

- ◆ systems for monitoring Strategy research to achieve objectives of quality and relevance.
- ◆ systems through which Strategy advisory bodies (like ANCAHRD), NHMRC, ARC and other Australian government research funding agencies can interact to discuss specific research priorities and programs.

Terms of Reference for the Discipline Specific Review Panels

In the context of assessing the scientific quality and international competitiveness of research, each Discipline Specific Review Panel will review and make recommendations on:

Research goals and priorities

1. The current strategic planning processes, goals and priorities and progress made towards meeting the stated goals / priorities;
2. The relationship of current and projected research activities to the stated goals and priorities of the Centres and the extent to which they reflect, and can inform, emerging priorities;
3. The extent to which the goals and activities reflect the needs of key stakeholders (ie Commonwealth and State/Territory policy makers, ANCAHRD, Australian Federation of AIDS Organisations (AFAO), Hepatitis C organisations, National Association of People Living with HIV/AIDS (NAPWA), the medical and research communities (including Australasian Society for HIV Medicine (ASHM)), and Aboriginal people and Torres Strait Islanders);
4. The contribution of each Centre's organisation and management structure to the attainment of the goals and its role in fostering interaction with each other and with ANCAHRD;
5. To assess the effectiveness and appropriateness of Centre mechanisms for providing scientific guidance and accountability with respect to research objectives, including the Scientific Advisory Committees where relevant.

Research dissemination and exchange

6. The nature, appropriateness and effectiveness of Centre mechanisms for disseminating research findings and information policy developments.
7. The extent and value of the collaboration of the Centres with researchers in the HIV/AIDS, hepatitis C and related areas (e.g. Drug and Alcohol Research Centres) and the Centres' success in encouraging leading researchers to focus attention on HIV, hepatitis C and related research.
8. The extent and value of Centres' relationships / collaborative arrangements with other key organisations, such as
 - ◆ centres funded under the Public Health Education and Research Program;
 - ◆ funding bodies;
 - ◆ government departments;

- ◆ the host university; and
 - ◆ international bodies, such as UNAIDS, World Health Organization (WHO) and overseas universities /research centres.
9. The extent and value of additional funding attracted by National Centres including:
- ◆ the extent to which this funding contributes to the Centre's primary goals.
 - ◆ the value to Australia of such external funding.
 - ◆ the capacity of existing Centres to attract and maintain external funding.
10. The extent and value of the training opportunities provided by the Centres for researchers and those working in areas relevant to the Centres' activities.

Other

11. Other matters considered relevant or which emerge during the Review.

For NCHECR only

12. Evaluate the cost-effectiveness, utility and efficiency of hepatitis C and STI surveillance as carried out by the National Centre in HIV Epidemiology and Clinical Research (NCHECR).

1.10 REFERENCES

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