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

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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


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 though 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.

<table>
<thead>
<tr>
<th>Number</th>
<th>Recommendation</th>
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<tr>
<td>6.</td>
<td>Clearer identification and championing of hepatitis C as an urgent national public health problem by the medical and public health community.</td>
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<td>7.</td>
<td>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.</td>
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<td>8.</td>
<td>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.</td>
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<td>9.</td>
<td>Implement a program to improve and expand current harm-reduction strategies, including:</td>
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<td>♦ implementing best-practice models for NSPs— involving training of NSP workers, better referral systems, and proactive local management systems to allay community concerns</td>
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<td></td>
<td>♦ increasing the availability of medical detoxification—with particular attention to accessibility outside metropolitan areas</td>
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<td>♦ improving access to substitution therapies such as methadone and buperonorphine</td>
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<td>♦ investigation of other approaches to reducing injecting as the preferred method of drug delivery</td>
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<td>10.</td>
<td>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.</td>
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<tr>
<td>11.</td>
<td>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.</td>
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<td>12.</td>
<td>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.</td>
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<td>13.</td>
<td>Develop and implement improved surveillance methods for hepatitis C.</td>
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<td>Recommendations</td>
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<td>14.</td>
<td>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.</td>
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<td>15.</td>
<td>Ensure greater involvement of at-risk groups in strategy planning and implementation— with particular attention to the use of peer-group education.</td>
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<td>16.</td>
<td>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.</td>
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<tr>
<td>17.</td>
<td>Review and implement other specific recommendations of the Hepatitis C Strategy Review Team, consistent with the recommendations of the Lead Review Team.</td>
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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 – NHMRC 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.

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<td>18.</td>
<td>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.</td>
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<td>19.</td>
<td>For the Population Health Division, convene, at least yearly, round tables of stakeholders, to identify and set priorities for strategic research.</td>
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<td>20.</td>
<td>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.</td>
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<td>21.</td>
<td>Begin negotiations to identify funding for and a process for establishing a research program for hepatitis C.</td>
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<td>22.</td>
<td>Monitor the funding transition process to ensure that relevant strategic research is not interrupted.</td>
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<tr>
<td>23.</td>
<td>Review and implement all specific recommendations of the Strategic Research Review Panel, consistent with the recommendations of the Lead Review Team.</td>
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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.

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.


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;
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.


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 (i.e 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


REVIEW OF THE NATIONAL HIV/AIDS STRATEGY
1999–2000 TO 2003–04

GETTING BACK ON TRACK …
REVITALISING AUSTRALIA’S RESPONSE TO HIV/AIDS

July 2002

Dr Rob Moodie
Professor Anne Edwards
Senator Marise Payne
2.1 SUMMARY AND RECOMMENDATIONS

2.1.1 Summary

In January 2002 the Minister for Health and Ageing, Senator the Hon Kay Patterson, decided that a review of the National HIV/AIDS Strategy 1999–2000 to 2003–04 should be undertaken, to provide a clear picture of achievements thus far under the Strategy and to guide the next phase of Australia’s public health response to the HIV/AIDS epidemic.

The Review Panel found that the fourth National HIV/AIDS Strategy has been effective in working towards its stated goals. It has continued Australia’s very cost-effective public health approach to HIV/AIDS, has built on the basic tenets of previous Strategies, and has reaffirmed the partnership approach. It has also tackled important challenges such as the creation of a supportive, non-discriminatory legal, social and economic environment. Additionally, significant progress has been made in increasing the length and quality of life of people living with HIV and AIDS.

But HIV/AIDS continues to be a serious cause of preventable morbidity and mortality, both in Australia and in our region. Despite the gains made during the past three years, the Review Panel is convinced that a major revitalisation of Australia’s response to HIV/AIDS is required. A fifth National Strategy is warranted in order to re-energise our efforts, and the Panel recommends the establishment of new governance structures and processes to advise the Minister and the Commonwealth Department of Health and Ageing. The Panel considers that the partnership approach remains the most effective and efficient way of ensuring an adequate response to HIV/AIDS in Australia.

The following are some of the more notable challenges we still face:

♦ the changing nature of the HIV/AIDS epidemic in Australia and in the region, including significant increases in HIV diagnoses in some states

♦ continuing unacceptably high levels of unprotected anal intercourse and of gonorrhoea among men who have sex with men

♦ developing the ability to measure the adequacy of program activity at the local level and to account for funding for this purpose at the state and territory level

♦ diminished support for harm-reduction approaches and the potential for an explosive spread of HIV among injecting drug users

♦ ‘prevention-free’ custodial settings

♦ the inadequacy of and lack of consistency between surveillance systems for HIV and STIs

♦ the declining leadership role of the Commonwealth

♦ the need for more effective ministerial advisory mechanisms
the increasing need for the Commonwealth to develop and implement a whole-of-government approach to many matters associated with HIV/AIDS domestically, as well as the need to do more about HIV in our region.

The Review Panel discusses these challenges in this report and makes recommendations designed to provide the basis for finding effective solutions through the development of a fifth National HIV/AIDS Strategy.

### 2.1.2 Recommendations

The Review Panel recommends as follows:

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<th>29.</th>
<th>That a major new national education program on prevention be developed with the states and territories and key stakeholders—for the term of a fifth National HIV/AIDS Strategy and beyond—to decrease rates of unprotected anal intercourse, related STIs (gonorrhoea and chlamydia) and HIV transmission among men who have sex with men. This program should include, among other things:</th>
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<td>development and enforcement of agreed codes of conduct within all ‘sex on premises’ venues—including prevention education, condom distribution, promotion of HIV and STI counselling and testing, and promotion of non-occupational post-exposure prophylaxis for men</td>
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<td>development of new communication and community-based programs to reach young gay men, men who have sex with men but are not attached to the gay community, and gay men living in rural and remote areas</td>
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<td>development of a national annual sexual health check-up program for men who have sex with men, along with continuing public campaigns to increase the availability of and participation in counselling and testing</td>
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<td>review and updating of HIV-testing guidelines.</td>
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<th>That harm-reduction approaches, in their broadest sense, be strongly supported from the funding and policy level-perspectives. This includes:</th>
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<td>needle and syringe programs</td>
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<td>development of best-practice models for needle and syringe programs—for example, referral systems and local community management systems involving police, traders, residents, pharmacists, local government, non-government organisations and magistrates courts</td>
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<td>support for expanded hours</td>
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<td>provision of sterile water</td>
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<td>availability of medical detoxification</td>
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a broad range of substitution therapies—methadone, buprenorphine, and so on
availability of abstinence-based therapies
connections to and from the prison systems—see also recommendation 32
peer education programs
an education program for decision makers and the general community.

31. That new approaches to harm reduction—such as the use of supervised
injecting facilities, syringes with retractable needles, and medically prescribed
heroin—be rigorously evaluated.

32. That, in close collaboration with the states and territories, a national HIV
prevention and care program for prisons be developed. This should include:

- increased availability and uptake of both substitution-based and abstinence-based
treatments for drug users in prisons
- strong continuing engagement with prison officers and their unions to develop
programs—for example, in-prison needle and syringe exchange programs—that
benefit the officers as well as the prisoners.

33. That culturally and linguistically diverse communities at high risk of HIV
transmission be added to the other priority groups in the current Strategy—
Aboriginal and Torres Strait Islander peoples, people who inject drugs, people
in custodial settings, sex workers, and the male and female partners of these
people—and that a national program be developed with the states and
territories to reduce transmission in these communities.

34. That the next-generation national program of epidemiological, behavioural and
clinical surveillance be developed. This should include new testing
technologies, such as the detuned ELISA test, and indicators such as HIV
testing patterns, viral load, unprotected anal intercourse, condoms, and needles
and syringes.

35. That one of the main performance indicators for the National Centre in HIV
Epidemiology and Clinical Research be the extent to which the Centre builds
surveillance capacity with the states and territories.

36. That a national workforce-development program be designed and
implemented with the states and territories and key stakeholders.

37. That the Commonwealth revitalise its national leadership role through
enhanced funding, policy development, research, overall coordination, support
for the partnership, and international assistance.
38. That the current governance structure be dissolved and that four advisory committees be established—HIV, Hepatitis C, a Legal Committee, and an Indigenous Australians’ Sexual Health Committee—with coordination achieved through a committee of Chairs and Deputy Chairs.

39. That a Governance Charter be developed to clearly define the respective roles of the different elements of the new governance structures—for example, advisory committees, working groups and government departments.

40. That the Commonwealth Parliamentary Liaison Group be revitalised and supported and be seen as a very important element of the national response.

41. That consideration be given to developing a national strategy for STIs, to rekindle interest in working with Australia’s young people.

42. That a framework for continuing evaluation of the National HIV/AIDS Strategy be developed and implemented.

43. That a biennial, comprehensive study to identify, document and track over time the responses to HIV/AIDS at the national, state and territory and local levels be developed and carried out.

44. That resources be specifically dedicated to the establishment of new and continuing capacity to analyse and monitor the economic benefits and costs to government and the community of HIV programs and their components and sub-components.

45. That the National Centres in HIV Research commit increased effort and resources to understanding changing trends in unprotected anal intercourse, gonorrhoea and HIV infection in Victoria and South Australia.

46. That the agenda for the National Centres in HIV Research be set by means of a consultative process at three-year intervals, with provision for rapid responses to emerging problems as they arise.

47. That a cross-sectoral working group—with representation from the Department of Health and Ageing, AusAID (the Australian Agency for International Development), the Department of Foreign Affairs and Trade, and the Department of Immigration and Multicultural and Indigenous Affairs, plus co-opted external experts—be established to expand and coordinate Australia’s international role in HIV/AIDS. The working group should report to the HIV Committee of the new governance structure.

48. That the Department of Health and Ageing work with AusAID to develop a mechanism for improving the participation of Australian experts in our international response.

49. That task-focused, time-limited working groups—reporting to the HIV Committee—develop national approaches to complex cross-government questions such as:
♦ income support for people living with HIV/AIDS
♦ access to therapies
♦ models of care for people living with HIV/AIDS, including evaluation of the GP Enhanced Care Pilot Project in New South Wales
♦ mental illness services
♦ supported accommodation and housing for people living with HIV/AIDS
♦ Medicare ineligibility.

50. That a fifth National HIV/AIDS Strategy be developed to further develop and implement the foregoing recommendations. The Strategy should cover the three years from 2004–05 to 2006–07 and should be reviewed in mid-2006.
2.2 CONTEXT

2.2.1 Introduction

The National HIV/AIDS Strategy 1999–2000 to 2003–04, called Changes and Challenges, was launched in June 2000. It stresses the need for monitoring and evaluating Australia’s response to the HIV/AIDS epidemic, to ensure that policy and practice are based on the best available evidence and information, and it proposes an independent, external mid-term review as an important mechanism for this purpose. In January 2002 the Commonwealth Minister for Health and Ageing, Senator the Hon Kay Patterson, decided that a review of the National HIV/AIDS Strategy 1999–2000 to 2003–04 would be carried out in 2002, to guide the next phase of the public health response to the epidemic.

The HIV/AIDS Section of the Communicable Diseases and Health Protection Branch in the Commonwealth Department of Health and Ageing developed the Terms of Reference for the review in consultation with ANCAHRD, which is the Minister for Health and Ageing’s principal advisory body on implementation of the Strategy. Key stakeholders such as the Australian Federation of AIDS Organisations, the National Association of People Living with HIV/AIDS and the National Centres in HIV Research were involved in the development process through their representation on ANCAHRD.

Section 2.5 (Appendix A) shows the Review’s Terms of Reference. The review was conducted by an independent Panel whose members were:

♦ Dr Rob Moodie—Chair
♦ Professor Anne Edwards
♦ Senator Marise Payne.

2.2.2 Australia’s response to the HIV/AIDS epidemic

The Commonwealth Government launched Australia’s first National HIV/AIDS Strategy in August 1989. The Strategy reflected the principles espoused in the 1986 World Health Organization (WHO) Ottawa Charter for Health Promotion, and it provided a framework for an integrated response to the HIV epidemic and a plan for action across a range of policy and program activities. The primary aim was to stop the spread of HIV in Australia and to provide care and support for people affected by HIV.

The second National HIV/AIDS Strategy 1993–94 to 1995–96 (released in 1993) retained and refined the core elements of the first Strategy. The foundation continued to be a nationally coordinated approach underpinned by a partnership between government, affected communities, researchers, scientists and health professionals, and the strong focus on HIV education and prevention was maintained. The Strategy was implemented in the context of the Special Funding and Matched Funding
arrangements that existed between the Commonwealth and the states and territories for health financing.

At the request of the Federal Cabinet, a comprehensive review of the second Strategy was conducted in 1995, to assess the Australian response to the HIV epidemic to that point and to determine whether another national strategy was necessary. Professor Richard Feachem was appointed to lead the evaluation and his report, *Valuing the Past ... Investing in the Future*, was published in September 1995.

On the basis of epidemiological, economic and behavioural data, extensive community consultation and analysis of outcomes, Professor Feachem concluded that Australia’s response to the HIV/AIDS epidemic had been effective, appropriate and achieved at reasonable cost. His report underlined the importance of having a third National HIV/AIDS Strategy—with adequate funding and for a longer term. It recommended maintenance of the core aims of the former Strategies, with refined objectives; it also recommended situating HIV within the context of a broader communicable diseases and sexual health framework.

Following the Feachem report, the third National HIV/AIDS Strategy 1996–97 to 1998–99, called *Partnerships in Practice*, was developed and released in 1996. Like its predecessors, the third Strategy set out to reduce the number of HIV infections as well as HIV’s impact on people affected by the virus. It was based on three principles: working towards or maintaining non-partisan political support; the HIV partnership; and involving those communities most affected by HIV in all elements of the response. The five priority areas of activity that were identified—education and prevention, treatment and care, research, legal and ethical matters, and international assistance and cooperation—maintained and built on the central elements of the earlier Strategies.

The third National Strategy was implemented at a time of far-reaching reform in the health sector, especially in public health. Of particular relevance to HIV/AIDS was the change in Commonwealth–state funding arrangements for national public health programs: there was a move away from the earlier issue-specific funding arrangements to the development of Public Health Outcome Funding Agreements (PHOFAs) and broad-banded funding.

The Australian National Council on AIDS and Related Diseases (ANCARD) reviewed the third National HIV/AIDS Strategy in 1999. It found that the third Strategy had been effective in working towards its stated goals but that much remained to be done. At the same time, treatment options for HIV-positive people were greatly expanding, creating a number of new challenges for the prevention and treatment and care components of the national response. The review concluded that a national strategy approach continued to be the most effective and efficient way of ensuring an adequate response to HIV/AIDS and that, despite the many achievements of the previous Strategies, further concerted action was essential to effectively contain and treat HIV in Australia.

The fourth National HIV/AIDS Strategy 1999–2000 to 2003–04 was developed in response to ANCARD’s recommendations and in consultation with key stakeholders in the HIV partnership.

The National HIV/AIDS Strategy 1999–2000 to 2003–04 builds on the achievements of its three predecessors by retaining the underlying partnership approach, which involves affected communities; governments at all levels; medical, scientific and health care professionals; and, importantly, non-partisan political support. Like the third Strategy, the fourth Strategy is framed in the context of related communicable diseases and sexual health. It also emphasises the need for greater coordination of effort across the partnership and greater integration with related government policies such as the National Drug Strategic Framework and the first National Hepatitis C Strategy.

As with the previous National HIV/AIDS Strategies, the fundamental purpose of the current Strategy is to safeguard the health of all Australians in relation to HIV/AIDS by eliminating the transmission of HIV and minimising the personal and social impacts of HIV infection. The Strategy identifies five priority areas of activity to guide implementation:

♦ HIV/AIDS-related health promotion—including disease prevention
♦ treatment, care and support
♦ research
♦ international assistance and cooperation
♦ development of a legislative and policy framework that facilitates access to useful information for people at risk of HIV infection and people living with HIV/AIDS and that protects the human rights of those people—an ‘enabling environment’.

Six population groups are specified as priorities for prevention, education and health-promotion activities:

♦ gay and other homosexually active men
♦ Aboriginal and Torres Strait Islander peoples
♦ people who inject drugs
♦ people in custodial settings
♦ sex workers
♦ people living with HIV/AIDS.

2.2.4 HIV/AIDS program funding

Sustained commitment of resources by the Commonwealth and the state and territory governments has been an essential component of Australia’s relative success in
combatting HIV/AIDS. In 2001–02 the Population Health Division of the Commonwealth Department of Health and Ageing committed approximately $14 million to support nationally focused HIV/AIDS education and prevention, research, and treatment and care programs and activities. (Additional funding is allocated through the Department’s Office for Aboriginal and Torres Strait Islander Health to assist with implementation of the National Indigenous Australians’ Sexual Health Strategy.) In the Commonwealth’s response to the HIV/AIDS epidemic, care has always been taken to ensure that key priorities and objectives are met and that the benefits and economies of scale to be gained from collaboration with related health initiatives are realised.

In addition, a notional figure of $25 million, based on allocations made under the previous Matched Funding arrangements for HIV/AIDS, was incorporated in the broad-banded PHOFAs with the states and territories at the beginning of 1997–98. The broad-banding is designed to give the states and territories greater flexibility to respond appropriately to public health concerns in their regions: the amount of funding for each public health program is not separately identified. For 2001–02, the PHOFA base funding to the states and territories for national public health programs was approximately $120.1 million.

It should be noted that the Review Panel was unable to obtain reliable information on Commonwealth and state and territory funding in recent years, making it impossible to discern trends and to validate claims made by several Review participants that the level of resources being expended on HIV is diminishing.

Public hospital services (delivered on site in a public hospital or as outreach services) and general practitioner services are funded through the Australian Health Care Agreements (1998 to 2003) and Medicare respectively. The Pharmaceutical Benefits Schedule and the Pathology Services Table of the Medicare Benefits Schedule offer affordable access to HIV treatments and funding for the investigation of HIV infection.

2.2.5 The changing HIV/AIDS epidemic

From 1990 to the end of 2000 consistent declines in the number of new HIV diagnoses were recorded in Australia. But this situation is changing: there were 774 new diagnoses in 2001, a 4.6 per cent increase on the 740 reported in 2000 (National Centre in HIV Epidemiology and Clinical Research 2002b). Other evidence suggests that there are serious grounds for concern that the number of HIV notifications will continue to rise if we do not considerably reinvigorate our response.

Victoria has witnessed the greatest and most persistent recent rises in the number of new HIV diagnoses: in that state 218 cases of HIV were diagnosed in 2001, a 56 per cent increase on the 1999 total of 139 cases. Within this, there was an 88 per cent increase in diagnoses among men who have sex with men—from 80 in 1999 to 150 in 2001. This increase continued into the first quarter of 2002. In South Australia the number of HIV notifications increased from 23 in 2000 to 42 to 2001 (National Centre in HIV Epidemiology and Clinical Research 2002b).
In the last few years there has also been a continuing, steady increase in diagnoses of gonorrhoea, especially in men who have sex with men. The number of notifications of rectal isolates of gonorrhoea in New South Wales rose from 73 in 1996 to 182 in 2000; in Victoria the number rose from 56 in 1996 to 91 in 2000 (National Centre in HIV Epidemiology and Clinical Research 2001).

Studies examining the sexual behaviour of gay men have found high and increasing levels of unprotected anal intercourse, the levels being higher in Sydney and Adelaide than in Melbourne, Perth and Brisbane.

Why have there been significant rises in HIV in Victoria over the past two years and in South Australia in the past year and not in other states, despite the fact that levels of unprotected anal intercourse and gonorrhoeal rectal isolates are highest in Sydney? Some researchers and educators have argued that gay men in New South Wales have a very sophisticated approach to ‘negotiated safety’ and ‘strategic positioning’ and are using their knowledge of their ‘low’ viral load to diminish their risk. Such an approach requires knowledge of one’s own HIV status and that of one’s partner. The concept of ‘negotiated safety’ is patently not working in Victoria, where one of the worrying features of the current increase in HIV infections is the relatively low level of testing and counselling, despite the greater availability of information about increased levels of infection in the past 12 months. Many people who are at risk are unaware of their status: this is attested to by the fact that 41 per cent of those diagnosed during 2001 had not previously been tested for HIV.

The availability of HAART has not only changed the survival rates of people with HIV: it has also changed the nature of HIV/AIDS, from a rapidly terminal disease to a complex, chronic one. The consequent change in perceptions of the disease is thought to be an underlying factor in the increasing rates of unprotected anal intercourse. With the success of HAART also comes increasing toxicities, as well as increasing viral loads resulting from resistance to therapy. Management of the many medical and social factors affecting people living with HIV is becoming ever more complex.

HIV rates among Aboriginal and Torres Strait Islander peoples remain relatively low, despite very high levels of STIs. Why this is still the case—many years after the first reported case of HIV in this population group—remains a puzzle. It seems that it is a matter of good luck rather than good management. One argument is that the high STI rates are attributable to repeated re-infection in quite a small number of people; this is often associated with serious social disintegration and alcohol abuse, and HIV has simply not entered these sexual networks.

HIV levels among entrants to prison are also still relatively low, as are the rates among injecting drug users generally and among Indigenous injecting drug users. This contrasts with the consistently high rates of hepatitis C infection in these groups.

Concern has been expressed about the potential for emerging heterosexual transmission in culturally and linguistically diverse communities and rural and remote communities. The national HIV data do not yet seem to reflect this:

While the total number of new HIV diagnoses has declined steadily, from 910 in 1996 to 745 in 2000 … the number of diagnoses attributed to heterosexual contact has remained relatively stable at around 150 per year, with approximately 60–70% attributed to people from a high prevalence country or with partners from a high...
Changes in the political and social environment

Several challenges have arisen from changes in the political and social environment, suggesting that, to some extent, Australia has become a victim of its own success.

As the number of new diagnoses of HIV and the mortality from AIDS have declined so too has the public profile of HIV/AIDS in this country. This has been accompanied by a waning in public discussion about HIV and AIDS and greatly reduced interest in events such as World AIDS Day—other than interest in the epidemic in Africa and in Southeast Asia, although this interest is still small when one considers the magnitude of the epidemic.

Not surprisingly, given the success of prevention efforts and HAART after many years of high mortality and ‘emotional exhaustion’, a perception has arisen that AIDS is ‘over’. This has resulted in a degree of disengagement on the part of the gay community. In some states at least, there has been a reduction in the intensity and coverage of prevention and education programs.

It appears that in the past 15 years human resources within departments at the federal level and in Victoria and New South Wales have decreased, coincident with an increase in community capacity. If the wherewithal within government is reduced too much, the ability to coordinate and lead a whole-of-government approach could be seriously compromised.

The Commonwealth and state and territory governments have also evinced growing interest in, and emphasis on, evidence, outcomes and value for money.

Why invest in public health approaches to HIV?

In the last 20 years or so Australia’s response to HIV/AIDS has produced dramatic results: the peak of 1700 new HIV infections diagnosed in 1984 has fallen to an average of about 700 new infections a year in recent times. But, like many other public health programs requiring difficult and sustained behaviour change—examples are campaigns to reduce tobacco smoking, road trauma and skin cancer—substantial ongoing resources (human, financial and technological) need to be applied if we are to avoid significant increases in HIV infection rates in the coming years. In addition, and in contrast, HIV by its nature is a complex disease from the technical, behavioural, developmental and political perspectives, dealing as it does with sexuality, commercial sex, illicit drugs, human rights and marginalised groups.

The report of the recent Applied Economics review of Australia’s investment in HIV/AIDS public health programs states:

[The programs] have returned substantial positive net benefits. For all exposure groups, the present value of expenditures on education and prevention programs in 2000 prices discounted back to 1984 is $607 million. The estimated present value of the benefits derived from these programs is $3.149 billion. The estimated net benefit is therefore $2.541 billion. The conclusion that the HIV/AIDS education and
prevention programs provided positive net benefit is robust to changes in all three key underlying assumptions. (Applied Economics 2001)

This is consistent with the findings of the evaluation of the third National Strategy, which confirmed the very positive net outcome of Australia’s investment in HIV prevention (Department of Human Services and Health 1995).

**Why have separate governance, and funding, for HIV and hepatitis C?**

It is apparent to the Review Panel that the anticipated synergies to be derived from combining the governance of HIV and hepatitis C (and related diseases) have not eventuated. No evidence was presented to demonstrate the leadership or efforts made to realise such synergies. The Panel can only conclude that little or nothing has been done to make combined governance for HIV and hepatitis C actually work.

Another important factor is that the organisations working on HIV, apart from those working on HIV among injecting drug users, have little in common with those working on hepatitis C, and there is little overlap in communities of interest. If one were looking for synergies, it might make more sense to look for them between hepatitis C and the National Drug Strategic Framework, or between HIV/AIDS and a strategy dealing with STIs.

In addition, the HIV/AIDS governance structures have had little impact on ‘related diseases’: apart from the Indigenous Australians’ Sexual Health Strategy, these related diseases have never been operationally defined or appropriately resourced.
2.3 ANALYSING THE EVIDENCE

The Review Panel had neither the time nor the capacity to evaluate in detail all facets of the current National HIV/AIDS Strategy. Instead, it has relied on evidence presented to it through written submissions, oral presentations, interviews and background material to formulate its views. This section analyses and discusses the evidence within the scope of the Terms of Reference.

Overall, the submissions were relevant and well prepared; those from non-government organisations were of a particularly high standard. In addition, the Panel appreciated the written comments provided by the health departments of New South Wales, South Australia, Western Australia and Queensland. It is disappointing that Tasmania, Victoria and the two territories did not make submissions.

The Review Panel considers that one of the main shortcomings of this Review is the lack of an evaluation framework for the fourth Strategy and the lack of evaluation studies. There seems to be little information about the resources (inputs), products (outputs) and outcomes from investments in HIV/AIDS during the fourth Strategy.

2.3.1 Effectiveness

The first term of reference requires the Review Panel to:

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.

The broader communicable diseases framework

It is important to emphasise that HIV/AIDS continues to be a major cause of preventable morbidity and mortality in Australia, with serious consequences for the treatment and care of people living with HIV. The Review Panel notes that, without a well-informed and well-implemented continuing response, Australia’s epidemic could
deteriorate markedly in a relatively short time and that the implications of this for the
Australian health care system would be sizeable and manifold.

The evidence before the Review Panel indicated that there was broad support for
placing the HIV/AIDS Strategy within a broader sexual health and communicable
diseases framework but that real planning and implementation must occur if the links
and synergies are to have their desired effect. There was relatively widespread
concern among Review participants at the prospect of HIV/AIDS ceasing to maintain
its own distinct profile.

Implementation

The fourth National HIV/AIDS Strategy was developed following widespread
consultation. Key members of the HIV partnership endorsed the final document, and
it was published in 2000.

Australia has had some notable successes during the term of the Strategy. HIV
infection rates decreased early in the period, although they increased in 2001–02.
Deaths from AIDS-related illnesses have steadily declined from the already relatively
low levels and, while the spectres of side effects and resistance exist, many HIV-
positive people continue to enjoy relatively good health. To this extent, it can be
argued that the Strategy has been implemented to a large degree.

Opinions about aspects of the Strategy’s implementation vary greatly. Some
stakeholders consider that the Strategy has been an instrument of consolidation.
Others feel that its implementation has been seriously undermined by various factors:
for example, there was widespread complaint about the difficulty of tracking funding
(at both the Commonwealth and the state and territory levels) and dissatisfaction with
the role and responsibilities of ANCAHRD and the lack of support for situating
hepatitis C advisory structures with those for HIV.

Many Review participants pointed to the lack of funding accountability on the part of
the Commonwealth and the states and territories as a major impediment to
implementation. They claimed it has become much more difficult to ascertain and
track the level of Commonwealth government spending in recent years, because funds
are now being disbursed among various bodies with various responsibilities—
including, for instance, the Office for Aboriginal and Torres Strait Islander Health in
the Department of Health and Ageing—rather than by specific program
appropriations. The PHOFAs between the Commonwealth and the States and
Territories were seen as very problematic for monitoring expenditure for HIV
initiatives, especially State and Territory spending on health-promotion campaigns
targeting gay men. This raises the question of whether adequate levels of funding
have been maintained by the states and territories, a matter dealt with in more detail in
Section 2.4. The Review Panel was unable to ascertain the level of funding that has
underwritten the Strategy; nor was it able to make any comparisons with investment
levels during previous HIV/AIDS Strategies.

Another critical concern is the state of the HIV/AIDS partnership. This is discussed in
Section 2.3.2, but it should be borne in mind that the health or otherwise of the
partnership is perceived to have a direct influence on the degree and effectiveness of
the Strategy’s implementation. The Panel considers that the current Government
places high value on the establishment and maintenance of an effective, working partnership in the HIV/AIDS area. A number of other examples of the value placed on partnership were also cited, including in connection with domestic violence and the health of Indigenous Australians.

Some participants argued that the current National HIV/AIDS Strategy does not take account of the need for effective evaluation of implementation outside a formal review process. They claimed that the Commonwealth is now less directly involved in program activities and, with the advent of the PHOFAs, the focus has shifted to the states and territories, who now undertake the majority of program activity.

Most submissions claimed that ANCAHRD’s dual role—being responsible for both hepatitis C and HIV—diminishes its capacity to adequately concentrate on either.

**Achievement of Strategy objectives**

**Creation of an enabling environment**

Review participants considered that, thus far during its term, the Strategy has achieved some notable successes in relation to establishing and maintaining an enabling environment. Within this context, the Review Panel is impressed by the achievements of the ANCAHRD Legal Working Party in bringing change and awareness in areas as diverse as health privacy, human rights, anti-discrimination, public health and criminal law, and the sex industry. One example of this innovative work is the development of a Rights Analysis Instrument (measuring legislative reform) through which Australia might monitor its progress in achieving real equality for minority groups identified by the Strategy.

The issue of greatest concern to Review participants was the impact of current Commonwealth policies relating to illicit drugs and injecting drug use. The majority of submissions asserted that harm-reduction activities were being affected by a change in political emphasis and direction and that efforts were being too strongly directed at supply reduction. There was a perception that education and prevention initiatives for injecting drug users were in decline, paving the way for a potentially catastrophic change in the HIV/AIDS epidemic. It was also suggested that the culture of illicit drug use was changing—a move from heroin to amphetamine use, in the wake of a shortage in the heroin supply—but that there had been no corresponding change in HIV prevention and education campaigns. Further, it was argued that Commonwealth funding for treatment programs for illicit drug use might be better invested in the most effective programs, such as medicated withdrawal and expansion of substitution therapy, in addition to abstinence-based therapy.

All Review participants agreed that the Commonwealth should ensure that there continues to be non-partisan, whole-of-government support for the response to HIV/AIDS. The Review Panel is strongly appreciative of the enabling political environment made possible by bipartisanship in the past and considers its continuance a prerequisite for any future strategic success. Revitalisation of the Parliamentary Liaison Group was proposed by some as a useful way of stimulating and sustaining this bipartisan support.
**HIV/AIDS-related health promotion, including disease prevention**

This Strategy, like its predecessors, places strong emphasis on prevention and health promotion. This has meant that health-promotion programs continue to make up a large proportion of the initiatives under the Strategy. A wide range of national information resources have been produced, and various education programs have been developed—for schools, for specific community groups, for sporting clubs, and so on. This has made an important contribution to reducing HIV transmission.

But Review participants were of the view that commitment to health-promotion programs, at both federal and state and territory levels, has eroded somewhat. Most concerns stemmed from a perception that real funding for programs at the state and territory level had been reduced, particularly for community programs, but that this could not be confirmed because of the nature of the PHOFAs. Despite the lack of hard data, the Review Panel feels that significant under-resourcing is occurring in health departments at both jurisdictional levels, and it is concerned at the possible loss in the public sector of the ‘critical mass’ and knowledge needed to support the response.

Many participants also referred to the need to pay much more attention to the epidemic—both existing and potential—among people in custodial settings. Conditions in prisons were described as falling well short of good practice for prevention and health promotion, especially given the often short-term stays in custody, the movement of inmates within the prison system, and the types of behaviour (injecting drug use and forced and consensual unsafe sex between men) common in custodial institutions.

**Treatment, care and support**

Review participants concentrated on the changing nature of living with HIV—namely, that the virus is now a chronic illness and that infection is treated in the context of a more ‘medicalised’ environment than ever before. This situation has a number of consequences for people living with HIV and AIDS.

Prime among these is the need to consult a large number of medical professionals (and pay each one) and the need to manage increasingly complex treatment regimes and a multitude of side effects. A number of participants proposed the implementation of a ‘one stop shop’ model, where a number of medical services can be accessed at one location. The GP Enhanced Care Pilot Project in New South Wales, currently under way with Commonwealth funding, was cited as a commendable move; there were calls for it to be extended.

Most submissions also highlighted the importance of redressing the increasingly evident shortfall in the provision of mental health care for people living with HIV/AIDS. The growing complexity of living with HIV as a chronic illness means that the incidence of a broad range of mental health problems—particularly depression and dementia—among People Living with HIV/AIDS (PLWHA) is rising.

Further, on the basis of the evidence before it, the Review Panel considers that accommodation and housing support for PLWHA (of whom over 30 per cent live below the poverty line) seem to be inadequate.
Another concern raised was that a number of drug companies appear to be reluctant to make new therapies available through the Special Access Scheme and that this has potentially dire consequences for many PLWHA currently obtaining medication through the Scheme. The Review Panel did not receive detailed evidence about this.

In the Panel’s view, the changing nature of treatment and care for PLWHA raises larger questions about the adequacy of current health system financing for HIV, and the subject should be examined in more detail.

Research

Research was not a primary focus of this Review because a concurrent review is focusing specifically on research related to the Strategy.

Nevertheless, broad support was expressed for HIV-related research and for the National Centres in HIV Research, and there was strong support for preserving an adequate level of resources for this purpose. The Review Panel notes the impressive reputation of Australian HIV researchers, and it reiterates the sentiments of the Strategic Research Review Team—that continued investment in a dedicated HIV research program is critical to a successful response to the epidemic.

As noted in Section 2.4, there are some major gaps in economic research, in understanding the rise of HIV in Victoria and South Australia, in surveillance, and in measuring Australia’s response to HIV.

International assistance and cooperation

Internationally, Australia has been a very important and active participant in working to curb the HIV epidemic since the early 1980s. This has continued during the term of the current Strategy, with the HIV partnership working successfully on a number of fronts. For the most part, AusAID has led Australia’s international efforts, although important and notable contributions have been made by other sectors, particularly Australian-based HIV/AIDS non-government organisations and the Department of Health and Ageing.

The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) took place in mid-2001, and Australia was represented by deputations from AusAID, the Department of Health and Ageing, and the Australian Federation of AIDS Organisations. Australia co-chaired the preparatory sessions and played a sizeable role in drafting the resultant declaration.

In addition, in October 2001 Melbourne hosted the International Congress on AIDS in Asia and the Pacific. As host nation, Australia was very well represented, and this was an opportunity to showcase Australia’s achievements in HIV/AIDS to the rest of the region. Coinciding with the Congress was the Asia-Pacific Ministerial Forum on HIV and AIDS, which was sponsored by AusAID at the instigation of the Minister for Foreign Affairs and Trade, the Hon Alexander Downer, MP. The Forum aimed to heighten awareness of HIV among Ministers responsible for health (and other ministers) in the region and to facilitate the development of strategies for effective action against the virus in participating countries.
Many submitters to the Review felt that Australia’s role in responding to the regional epidemic needs to be clarified and extended and that there has been insufficient linkage between the domestic response and the regional and international responses. This is discussed further in 2.3.4.

**The priority health needs of Aboriginal and Torres Strait Islander peoples**

The Review Panel received very little detailed commentary on the health needs of Aboriginal and Torres Strait Islander peoples.

Review participants noted the National HIV/AIDS Strategy’s linkages with the National Indigenous Australians’ Sexual Health Strategy; it was generally felt, though, that the challenges relating to Indigenous Australians’ health in general were yet to be taken up. The Review Panel does not have the capacity to explore in detail the impact of the HIV/AIDS Strategy on Indigenous Australians’ health and on the delivery of population health programs in Indigenous communities. Participants noted, however, that the ANCAHRD structure does include a committee with responsibility for Indigenous Australians’ sexual health and recommended that this be retained. They also suggested that mainstream population health areas need to be more mindful of Indigenous concerns when planning their activities.

The strong support from the previous Health Minister, the Hon Dr Michael Woodridge, for health initiatives specific to this population group was also noted.

### 2.3.2 The appropriateness, strength and effectiveness of the partnership

The second term of reference requires the Review Panel to:

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 Inter-governmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD);
- research, medical, scientific and health care professionals;
- the Non-Government Organisation and community sectors.

**The Commonwealth Government, state and territory governments, and local government**

The submissions revealed general agreement that the Commonwealth should continue to play a leadership role in tackling the HIV/AIDS epidemic, both within Australia and regionally. Some submissions called for the Commonwealth to lead more strongly and, specifically, for any future governance structures to focus on the provision of advice as opposed to taking an active implementation role.
A number of participants argued that there was a need to retain knowledge and capacity within government at both the state and territory and the Commonwealth levels to effectively support HIV policy development and program implementation. There was concern that this fourth Strategy does not clearly define the respective roles of government at all jurisdictional levels and that information exchange and accountability between levels of government have faltered as a result. The relationship between ANCAHRD and the IGCAHRD is relevant here, and the Review Panel notes reports from some participants that the two bodies have not always interacted effectively. It was considered that an effective working relationship between ANCAHRD and IGCAHRD (or their successors) was essential to the achievement of objectives under any future Strategy.

Associated with this is the argument put forward by some in the community sector that the Commonwealth Government’s focus on achieving key Strategy goals has tapered off.

**ANCAHRD and IGCAHRD**

Strong arguments were put forward by a majority of Review participants in relation to the effectiveness and future role of the ANCAHRD structure. At one end of the spectrum, ANCAHRD was viewed as a reasonably effective body that could be improved with modifications. At the other end, it was argued that ANCAHRD has become dysfunctional and requires radical reform.

The main criticisms concern the complexity and size of ANCAHRD’s structure, a lack of clarity about the role of members, and inexplicable criteria for membership in some instances. In addition, a number of participants alluded to an element of ‘territoriality’ on the part of a number of stakeholders who hold positions within the ANCAHRD structure. This was seen as posing a barrier to the effective functioning and evolution of the advisory framework as individuals and various stakeholders direct their efforts at maintaining status or protecting funding. It was broadly felt that communication within ANCAHRD could be improved.

In the absence of working synergies between HIV and hepatitis C, most comments favoured separate advisory mechanisms for HIV/AIDS and hepatitis C—reporting to and advising the Minister independently—in place of the current single advisory structure (ANCAHRD). A large number of participants argued for dissolution of ANCAHRD’s Clinical Trials and Research Committee and for its responsibilities to be taken up by the principal disease-focused committees. Views differed about the positioning of the Indigenous Australians’ Sexual Health Committee, but most participants considered that it should sit alongside, advise and have the same status as the disease-specific committees. Small, task-oriented or time-limited working parties were generally regarded as a more efficient way of dealing with particular issues.

Overall, participants’ primary theme was the lack of clarity about the role of ANCAHRD and how that body relates to the Department of Health and Ageing. This has produced tensions that need to be resolved in any future Strategy.

The Review Panel notes the submissions from a number of individuals sitting on ANCAHRD and its committees. It is surprised that ANCAHRD itself failed to present a submission.
Research, medical, scientific and health care professionals

The effectiveness of the partnership with respect to research is discussed in the report of the Strategic Research Review.

The non-government and community sector

There was universal agreement that the non-government and community sector has played an important and effective role in implementation of the fourth National HIV/AIDS Strategy. National non-government organisations such as the Australian Federation of AIDS Organisations and the National Association of People Living with HIV/AIDS have been active in the development of national policy, through representation on major Strategy committees and through political lobbying. They have also played a vital role in health-promotion and treatment and care initiatives. Any future Strategy should preserve the centrality of people living with HIV/AIDS.

However, a small number of Review participants asserted that some non-government organisations working in the sector were preoccupied with protecting their funding or position, or both, in the sector and that this was detrimental to the value of their contribution to the response, and to the partnership in general. There was also concern that some had lost their focus on their mission.

Some community sector participants claimed that people who have been part of the response since the early years are experiencing a sense of ‘exhaustion’ and that this is resulting in the disengagement of many gay men from the response. They argued that this trend needs to be reversed as a matter of urgency, to preserve gay men’s central place in the response and to keep open the communication channels with the health-promotion and prevention efforts.

2.3.3 Transferability to other chronic diseases

The third term of reference requires the Review Panel to ‘examine the transferability of approaches, partnerships, principles and services in HIV/AIDS to other chronic diseases’.

The Panel received few comments on this term of reference. The general opinion was that the HIV model had potential for applicability to other chronic diseases but that this would best happen through individual adaptation and tailoring by those with expertise in the particular area of application.

2.3.4 Australia’s role in the Asia–Pacific region

The fourth term of reference requires the Review Panel to ‘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’.

Many Review participants nominated HIV/AIDS in the Asia–Pacific region as an important emerging area of involvement for Australia.
The Review Panel acknowledges the major contributions of AusAID and the Minister for Foreign Affairs and Trade, the Hon Alexander Downer, MP, to dealing with HIV in Australia’s region. In particular, the Panel considers that Minister Downer and Dr Michael Wooldridge, the then Minister for Health and Aged Care, displayed strong leadership in convening the Asia-Pacific Ministerial Forum on HIV and AIDS, bringing together for the first time 33 Ministers from 31 countries in the region.

Participants generally agreed that a significant component of AusAID’s program has been devoted to HIV and that primary responsibility for Australia’s international contribution rests with that agency.

There was also general agreement that Australia has enormous potential to contribute but thus far has not done enough to apply its expertise and experience to help countries in the region tackle the epidemic. Most participants viewed the apparent lack of collaboration between relevant government agencies—particularly the Department of Health and Ageing and AusAID—to bring about a whole-of-government response to HIV in the region as a central factor in need of redress. In particular, a number of participants noted the need for a strong structural link between the Ministers for Health and Foreign Affairs, in recognition of the critical role effective measures will have in assuring ongoing development in the region.

It was considered that AusAID’s contractual requirements and procedures constrained access to the expertise in Australia and the deployment of that expertise in the region. The agency’s contracting procedures are currently under review, with a view to developing a more flexible and accessible process.

Even though AusAID established an HIV/AIDS Taskforce in early 2002, to better coordinate regional efforts, it was argued that government agencies such as the Department of Health and Ageing and Department of Immigration and Multicultural and Indigenous Affairs are still insufficiently involved.

### 2.3.5 Links with other national strategies

The fifth term of reference requires the Review Panel to:


A number of Review participants claimed that the synergies anticipated between the HIV/AIDS Strategy and Hepatitis C Strategy had not materialised to the extent originally envisaged. Almost without exception, participants considered that hepatitis C and HIV should continue to have separate strategies but that the single advisory mechanism is not working. Nevertheless, it was recognised that dialogue between the two areas has been important—particularly with regard to common risk groups—and that this should continue.

In the Review Panel’s opinion, although observations about the lack of synergies were common, it is difficult to see where efforts have been made to discover and act on the
synergies between the HIV/AIDS and Hepatitis C Strategies. In the absence of such efforts, the lack of synergies is almost a foregone conclusion.

The Review Panel considers that, on balance, good opportunities still exist for collaboration between the Strategies identified by the Terms of Reference, but this observation does not extend to the permanent sharing of advisory mechanisms.
2.4 NEW PRIORITIES, NEW DIRECTIONS

The sixth term of reference requires the Review Panel to:

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.

In this section, seven important areas of work for Australia’s future HIV/AIDS response are discussed:

♦ responding to the changing HIV/AIDS epidemic
♦ national leadership
♦ governance and advisory structures—principles of partnership
♦ measuring and understanding our response to HIV/AIDS
♦ research supporting the Strategy
♦ international and regional action
♦ a whole-of-government approach.

The recommendations that accompany them argue for a fifth National HIV/AIDS Strategy, with substantial changes to the current mode, level, scope and intensity of work.

2.4.1 Responding to the changing HIV/AIDS epidemic

In this section six questions are posed and discussed:

♦ Are our programs appropriate and sufficient?
♦ Do we really have an enabling environment?
♦ Are we doing enough in custodial settings?
♦ What are we doing about heterosexual transmission of HIV?
♦ Do our surveillance systems work well enough?
♦ Do we provide sufficient training and professional development?
Are our programs appropriate and sufficient?

If we look at the changing nature of the HIV/AIDS epidemic, it appears there are many areas where the breadth and intensity of Australia’s efforts are insufficient. Among these areas are the following:

♦ Rates of unprotected anal intercourse and related STIs, such as gonorrhoea, among men who have sex with men—especially young gay men, gay men in rural and remote areas, and men who have sex with men but are not attached to the gay community—are unacceptably high.

♦ At the places with greatest potential for reducing transmission—such as ‘sex on premises’ venues, beats, other gay venues, and via online cruising—there is a need to improve prevention education, condom distribution, promotion of counselling and testing for HIV and STIs, and promotion of non-occupational post-exposure prophylaxis for men who have sex with men.

♦ In ‘sex on premises’ venues, regulation of compliance with the ‘duty of care’ should be improved. This has been done in some states by working with venue owners, state and local governments, and AIDS Councils to develop codes of practice for these venues. However, developing support for, and enforcing, an agreed code of conduct calls for considerable work across the country. One anecdotaly raised concern that needs to be investigated is the availability of illegal ‘party’ drugs in ‘sex on premises’ venues, which may be increasing the risk of transmission of HIV and STIs.

♦ Detection and treatment of STIs—in their own right and as important co-factors for HIV transmission—need to improve. This is confirmed in Victoria, for example, by high levels (10–15 per cent) of asymptomatic gonorrhoea and chlamydia being found in men screened at ‘sex on premises’ venues and in HIV-positive men screened at HIV clinics.

♦ Greater access to and uptake of voluntary counselling and testing for HIV and other STIs among people at highest risk are necessary. As with many other public health problems, voluntary ‘screening’ is a vital part of the overall approach to decreasing morbidity and mortality.

We also need to increase our understanding of, and develop a response to, the impact that the high level of use of recreational drugs (as documented in a number of studies) might be having on the levels of unsafe sex.

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1 This refers to an assumed ‘duty of care’ on the part of venue owners, to help their clients stay as healthy as possible.
Recommendation 29

The Review Panel recommends that a major new national education program on prevention be developed with the states and territories and key stakeholders—for the term of a fifth National HIV/AIDS Strategy and beyond—to decrease rates of unprotected anal intercourse, related STIs (gonorrhoea and chlamydia) and HIV transmission among men who have sex with men. This program should include, among other things:

♦ development and enforcement of agreed codes of conduct within all ‘sex on premises’ venues—including prevention education, condom distribution, promotion of HIV and STI counselling and testing, and promotion of non-occupational post-exposure prophylaxis for men

♦ development of new communication and community-based programs to reach young gay men, men who have sex with men but are not attached to the gay community, and gay men living in rural and remote areas

♦ development of a national annual sexual health check-up program for men who have sex with men, along with continuing public campaigns to increase the availability of and participation in counselling and testing

♦ review and updating of HIV-testing guidelines.

Do we really have an enabling environment?

Much has been done during the term of the current Strategy to ensure that the legislative, regulatory and social environment continues to support the development and maintenance of safe behaviours. The legislative frameworks for anti-discrimination, regulation of the sex industry, human rights, and health privacy have been maintained and, in some cases, strengthened.

However, as was observed in many submissions, there seems to be a diminution in the ‘enabling environment’ for injecting drug users; this is attested to by difficulties in the operation of NSPs, either because of problems with public liability insurance or as a result of community pressure, and increasing police harassment deterring users from returning used syringes.

There has also been a significant increase in the overall number of injecting drug users and an increase in the number of users who may have a limited understanding of English and little connection to mainstream supports—information, testing and counselling, for example. It has been reported that injecting drug users no longer see HIV as a priority, their concern now being directed predominantly at hepatitis C.

An erosion of political (and some community) support for harm-reduction approaches seems to be occurring. This may be a result of the increasing number of injecting drug users, their increasing visibility, and the ‘nuisance’ caused by using on the street. It may also be a result of perceptions of harm reduction as consisting only of needle and syringe distribution, rather than the broad spectrum of activities including prevention
education and referral to detoxification, substitution therapy or abstinence-based therapy.

As part of the Needle and Syringe Program Returns-On-Investment Study (undertaken by Health Outcomes International and others), a recent review assessed the effectiveness of NSPs in 103 cities and towns (67 of them without NSPs). It found that the cities and towns that had introduced NSPs had a mean annual 18.6 per cent decrease in HIV seroprevalence compared with a mean annual 8.1 per cent increase in cities and towns that had not introduced NSPs. It also found that an estimated 25 000 HIV infections have been prevented among injecting drug users since the introduction of NSPs in Australia. Further, the study report states, ‘There have been significant financial savings accruing to government from the investment in NSPs to date, and … these savings will continue to accrue into the future’ (Department of Health and Ageing 2002).

There is also consensus that, because of successes to date, there is considerably less public discussion about and emphasis on the potential for an explosion of HIV among injecting drug users—as was witnessed in Vancouver.

A number of approaches to harm reduction are hotly debated, particularly the questions of supervised injecting facilities, syringes with retractable needles, and medically prescribed heroin. Given the nature of the debate, it is important that all these options be subject to rigorous scientific evaluation—as, for example, is happening with the trial of a supervised injecting facility in Sydney.

### Recommendation 30

The Review Panel recommends that harm-reduction approaches, in their broadest sense, be strongly supported from the funding and policy-level perspectives. This includes:

- needle and syringe programs
  - development of best-practice models for NSPs—for example, referral systems and local community management systems involving police, traders, residents, pharmacists, local government, non-government organisations and magistrates courts
  - support for expanded hours
  - provision of sterile water
  - workforce development
- availability of medical detoxification
- a broad range of substitution therapies—methadone, buperonorphine, and so on
- availability of abstinence-based therapies
- connections to and from the prison systems—see also recommendation 32
- peer education programs
- an education program for decision makers and the general community.
Recommendation 31
The Review Panel recommends that new approaches to harm reduction—such as the use of supervised injecting facilities, syringes with retractable needles, and medically prescribed heroin—be rigorously evaluated.

Are we doing enough in custodial settings?

The current National HIV/AIDS Strategy nominates ‘people in custodial settings’ as a priority population for HIV prevention, yet, as one Review participant described it, prisons appear to be ‘prevention-free zones’. On the basis of reported levels of injecting drug use in prisons and the very high rates of hepatitis C, the Review Panel can only assume that the relatively low levels of HIV are a matter of good luck, not good management.

We need a better understanding of the realities of prison behaviours, such as injecting drug use and forced and consensual unsafe sexual activity, which, despite attempts to prevent them in virtually every country, place a great number of prisoners at risk of HIV, hepatitis C and other blood-borne and STIs. There is also tremendous mobility of prisoners through the prison system—the huge majority are in prison for less than six months and often for drug-related offences—and from prison to prison.

Evidence from countries such as Switzerland suggests that NSPs in prisons are effective for both prisoners and prison staff—they are much less likely to receive a needlestick injury from a hidden needle and syringe—but these programs are yet to be introduced in Australia.

Progress in custodial settings will probably be slow, but it is essential that prison staff and management are consulted, educated and supported in developing more effective approaches.

Recommendation 32
The Review Panel recommends that, in close collaboration with the states and territories, a national HIV prevention and care program for prisons be developed. This should include:

♦ increased availability and uptake of both substitution-based and abstinence-based treatments for drug users in prisons
♦ strong continuing engagement with prison officers and their unions to develop programs—for example, in-prison needle and syringe exchange programs—that benefit the officers as well as the prisoners.

What are we doing about heterosexual transmission of HIV?
A number of Review participants expressed concern about the emergence of new HIV infections among people reporting heterosexual sex as their only risk factor.
Although, as noted in Section 2.2.5, the number of new HIV diagnoses attributable to heterosexual contact has been relatively constant in the past 10 or so years, there appears to be a need to develop prevention education and treatment and care programs for culturally and linguistically diverse communities that are at high risk.

**Recommendation 33**

The Review Panel recommends that culturally and linguistically diverse communities at high risk of HIV transmission be added to the other priority groups in the current Strategy—Aboriginal and Torres Strait Islander peoples, people who inject drugs, people in custodial settings, sex workers, and the male and female partners of these people—and that a national program be developed with the states and territories to reduce transmission in these communities.

**Do our surveillance systems work well enough?**

Although a great deal of excellent work has been done at the national level and in some jurisdictions over many years, some states still do not have active surveillance systems that can provide good information about the dynamics of the spread of HIV, which would in turn provide information about the epidemic and guide decisions about what can and should be done. Increased support is needed from the National Centres in HIV Research to assist state-level surveillance, which would in turn improve the quality of the national data. The increased effort would include coordination in relation to the following:

- data on individuals being tested as well as infected individuals
- the introduction of new technologies such as detuned ELISA testing, which can indicate new HIV infections, not just new diagnoses
- surveillance of viral loads
- behavioural surveillance of unprotected anal intercourse
- active surveillance for HIV, in addition to the current passive surveillance
- organised laboratory networks collaborating with researchers and clinicians.

Despite the interest in safe-sex education across the country for 15 years, we have no system of estimating the sales, distribution and availability of condoms, one of the key indicators of success. Estimates of condom use are gained from intermittent and periodic surveys such as the Gay Community Periodic Survey.

Similarly, there is no national database on the distribution and availability of needles and syringes.
Recommendation 34

The Review Panel recommends that the next-generation national program of epidemiological, behavioural and clinical surveillance be developed. This should include new testing technologies, such as the detuned ELISA test, and indicators such as HIV testing patterns, viral load, unprotected anal intercourse, condoms, and needles and syringes.

Recommendation 35

The Review Panel recommends that one of the main performance indicators for the National Centre in HIV Epidemiology and Clinical Research be the extent to which the Centre builds surveillance capacity with the states and territories.

Do we provide sufficient training and professional development?

Notwithstanding the excellent contribution of the Australasian Society for HIV Medicine, one of the symptoms of the declining interest in the response to HIV/AIDS is diminished investment of effort in the continuing training and professional development of our national workforce—be they NSP workers, primary care and specialist services, community educators, volunteers or senior decision makers. Big investments were made in this area in the early years of the epidemic in Australia; this needs to continue if we are to successfully prevent and treat HIV as well as maintain strong community and bipartisan political support.

Recommendation 36

The Review Panel recommends that a national workforce-development program be designed and implemented with the states and territories and key stakeholders.

2.4.2 National leadership

Bipartisan political support has been one of the central elements of Australia’s response since the beginning of the HIV/AIDS epidemic. The Review Panel congratulates all sides of politics in Australia for this and strongly endorses its continuity.

But the price of ongoing success with HIV prevention and treatment is eternal vigilance at the national level.

Some Review participants asserted that the Commonwealth’s role has diminished noticeably during the term of the current National HIV/AIDS Strategy, and the Review Panel is concerned lest the national response be allowed to continue to diminish in importance. The human and financial costs of avoidable and treatable HIV infection are too great for the Commonwealth to ‘take its hand off the tiller’.
The Review Panel acknowledges that all major stakeholders strongly support a continuing and stronger central leadership role for the Commonwealth. This should be in the following areas:

♦ funding—particularly for national peak organisations such as the Australian Federation of AIDS Organisations, the Australasian Society for HIV Medicine and the Australian Injecting and Illicit Drug Users League

♦ policy—which has to be developed and agreed to at the national level

♦ research—through specific directed research centres and projects that respond to national priorities

♦ coordination and partnership development—where the Commonwealth can act as an ‘honest broker’ between the states and territories and between the many community-based, non-government and government partners

♦ international assistance—which can really only be effective from a national standpoint

♦ the whole-of-government approach. In particular, the area of care and support for people living with HIV increasingly involves other sectors and government portfolios such as those responsible for labour, welfare, housing and transport.

**Recommendation 37**
The Review Panel recommends that the Commonwealth revitalise its national leadership role through enhanced funding, policy development, research, overall coordination, support for the partnership, and international assistance.

### 2.4.3 Governance and advisory structures: principles of partnership

Governance and advisory structures must be able to provide the best possible advice to and support for government and the Minister. Many submissions to the Review evinced a lack of confidence in the leadership, functioning, membership, and the cumbersome and expensive nature of the current advisory structure. There appears to be little effective communication and cohesion between the different parts of the structure, and concern was expressed that decisions were often made outside the various committees.

No submissions or oral presentations argued for retention of the existing structure and system of governance.

The structures and the accompanying processes should operate in such a way as to reflect the principle of partnership.

To improve the current structure, the Review Panel advocates the dissolution of ANCAHRD and its Clinical Trials and Research Committee and the establishment of four new committees—HIV, Hepatitis C, a Legal Committee, and an Indigenous Australians’ Sexual Health Committee (see Figure 2.1)—with a Coordinating
Committee consisting of the Chairs and Deputy Chairs of each Committee and reporting to the Minister.

**Figure 2.1 Proposed new governance structure**

The Review Panel recommends that the Minister appoint the Chairs and Deputy Chairs and have the option of appointing a rotating Chair and Deputy Chair of the Coordinating Committee or appointing an independent Chair and Deputy Chair. Membership of the advisory committees should represent a judicious balance between people with acknowledged expertise and representatives of key stakeholders: often, but not always, these two qualities are present in one person.

The setting up of time-limited, task-focused working groups at any time in order to solve problems is to be encouraged. These groups would report to the relevant committee.

In order to optimise the membership, leadership and operational functioning of the advisory structure, the Review Panel proposes the development of a Governance Charter, which will clearly define the membership criteria for and roles of the Coordinating Committee, the four advisory committees, the working groups, the Department of Health and Ageing, and other relevant departments. This would ensure that none of the advisory committees or the Coordinating Committee takes on an executive role, that they have clear processes for developing and providing advice, and that the Department of Health and Ageing retains its executive role.

The Review Panel further recommends that the Department increase its capacity to maintain the Commonwealth’s leadership role, to service the advisory committees, and to implement the advice it receives.

An important mechanism that needs to be revitalised is the Parliamentary Liaison Group, at the federal level and most probably at the state and territory level, to assist with feedback to and from key parliamentary figures.
Some Review participants suggested that there was no longer a public role for the key members of the current advisory structure. Given the reduced public visibility of HIV/AIDS at present, the Review Panel disagrees and strongly supports an enhanced public role for these people.

Many participants referred to the lack of a national strategy dealing with STIs. Despite noting previous failed attempts to develop a national sexual health strategy, they strongly supported the development of a strategy more focused on prevention and treatment of STIs.

**Recommendation 38**
The Review Panel recommends that the current governance structure be dissolved and that four advisory committees be established—HIV, Hepatitis C, a Legal Committee, and an Indigenous Australians’ Sexual Health Committee—with coordination achieved through a committee of Chairs and Deputy Chairs.

**Recommendation 39**
The Review Panel recommends that a Governance Charter be developed to clearly define the respective roles of the different elements of the new governance structures—for example, advisory committees, working groups and government departments.

**Recommendation 40**
The Review Panel recommends that the Commonwealth Parliamentary Liaison Group be revitalised and supported and be seen as a very important element of the national response.

**Recommendation 41**
The Review Panel recommends that consideration be given to developing a national strategy for STIs, to rekindle interest in working with Australia’s young people.

### 2.4.4 Measuring and understanding our response to HIV/AIDS

A number of submissions commented on the difficulty of monitoring and obtaining information about the level of funding support from the states and territories and claimed that this had been much easier through the Matched Funding Program. It would appear that, given the structure and reporting requirements of the current PHOFAs and the projected Health Care Agreements—combined with the fact that in many of the states and territories, particularly the larger states, the proportion of Commonwealth funding to state funding is relatively minor—seeking reporting through these mechanisms is neither a productive nor an efficient way of finding out about the response to HIV in Australia.
One of the shortcomings of this Review is the lack of an evaluation framework and the lack of evaluation studies to guide the Review. It seems that there has been minimal follow-up on much of the excellent work done for the evaluation of the third National HIV/AIDS Strategy. There is very little information about the resources (inputs), products (outputs) and outcomes from investments in HIV/AIDS during the fourth National Strategy.

We have in Australia the capacity to understand the status of the epidemic, but we have much less capacity to identify the magnitude and effectiveness of our responses to the epidemic. An example of this is the claim that the community response has diminished through lack of funding, yet the bigger AIDS Councils in particular have very large staff components—approximately 110 in New South Wales and 55 in Victoria. It seems we just don’t have the information to respond adequately to these claims.

Similarly, submissions from state governments claimed that there have been reductions in the Commonwealth contribution to the response to HIV through the PHOFAs, but the Review Panel has little or no evidence on which to judge the veracity of this claim.

**Recommendation 42**

The Review Panel recommends that a framework for continuing evaluation of the National HIV/AIDS Strategy be developed and implemented.

**Recommendation 43**

The Review Panel recommends that a biennial, comprehensive study to identify, document and track over time the responses to HIV/AIDS at the national, state and territory and local levels\(^2\) be developed and carried out.

### 2.4.5 Research supporting the Strategy

Generally, the submissions from policy makers and practitioners expressed a high degree of satisfaction with the quality and relevance of the epidemiological, behavioural and social research supporting the Strategy. In particular, there are effective links from research to practice and from practice to research.

Despite the value of the economic research noted in Section 2.2.5, one important gap involves continuing research into the cost-effectiveness of HIV prevention and treatment programs overall and their various components and sub-components. Given Australian governments’ and parliaments’ increasing focus on value for money, this capacity needs considerable development—as it does in other aspects of health care.

\(^2\) This would be of great use to all stakeholders: it would provide information far superior to that which could be obtained through the proposed use of the PHOFAs and Health Care Agreements as a means of reporting.
There has been much debate about the recent rises in HIV diagnoses in Victoria, yet the National Centres in HIV Research have done little to help elucidate the problem. Some Review participants suggested that the partnership should be more involved in setting the priorities of the National Centres.

**Recommendation 44**

The Review Panel recommends that resources be specifically dedicated to the establishment of new and continuing capacity to analyse and monitor the economic benefits and costs to government and the community of HIV programs and their components and sub-components.

**Recommendation 45**

The Review Panel recommends that the National Centres in HIV Research commit increased effort and resources to understanding changing trends in unprotected anal intercourse, gonorrhoea and HIV infection in Victoria and South Australia.

**Recommendation 46**

The Review Panel recommends that the agenda for the National Centres in HIV Research be set by means of a consultative process at three-year intervals, with provision for rapid responses to emerging problems as they arise.

### 2.4.6 International and regional action

The Review Panel examined only the role of the Department of Health and Ageing and its advisory structures in Australia’s international HIV/AIDS work: there was neither the opportunity nor the time to adequately assess overall performance in this area.

The Review Panel does note, however, that the Australian Government, through AusAID and the Department of Health and Ageing, is showing a great deal of commitment to HIV/AIDS in our region and, to a lesser extent, in Africa. The Panel appreciates that HIV/AIDS is not only a health problem and a human rights problem; it is also a major developmental challenge and is even being seen as a matter of national security in our region. Many Asian countries are now recognising the seriousness of the situation. The Association of Southeast Asian Nations (ASEAN) has also led initiatives in this regard.

Among the problems reported is the difficulty Australian institutions and experts experience in finding out about and gaining access to initiatives supported by AusAID, and particularly the tendering process. AusAID has already taken steps to remedy this by conducting a forum in April 2002 to bring together domestic institutions, experts and representatives of AusAID and the major aid contracting firms. To be effective, this needs to become a systematic, regular mechanism for improving the deployment of human resources in Australia’s international work;
examples are the Asia–Pacific Leadership Forum, assistance to the Seven Sisters, and direct country-to-country aid projects.

The Department of Health and Ageing has had an important role as a broker and facilitator (as well as a direct contributor) of the skills and experience developed in Australia and internationally in the last 20 years. Among the areas where it can make a further contribution are the following:

♦ development and maintenance of the human resource base to service the many AusAID- and non-government organisation-sponsored HIV/AIDS projects

♦ development, with AusAID, of a system that will ensure better integration of Australia’s research (and project) capacity to support aid projects. The primary focus of the research would be building capacity in other countries

♦ monitoring and supporting Australia’s role in the World Trade Organisation and in connection with the Agreement on Trade Related Aspects of Intellectual Property Rights as it affects HIV/AIDS and other relevant treatments

♦ monitoring and resourcing Australia’s response to the UNGASS and our involvement in the UNAIDS Programme Coordination Board and firmly encouraging the other co-sponsors—especially the World Bank, UNICEF, WHO and the United Nations Development Programme—to adequately support UNAIDS and each other.

Although partnerships do exist between AusAID and the Department of Health and Ageing, the Review Panel recommends that the Department’s international role be enhanced and that a formal relationship at officer level be developed. This is to ensure cross-department synergies; it should also include representation from the Department of Foreign Affairs and Trade and the Department of Immigration and Multicultural and Indigenous Affairs, and two representatives from the HIV Committee.

**Recommendation 47**

The Review Panel recommends that a cross-sectoral working group—with representation from the Department of Health and Ageing, AusAID, the Department of Foreign Affairs and Trade, and the Department of Immigration and Multicultural and Indigenous Affairs, plus co-opted representatives from the HIV Committee (or from elsewhere outside government)—be established to expand and coordinate Australia’s international role in HIV/AIDS. The working group should report to the HIV Committee of the new governance structure.

**Recommendation 48**

The Review Panel recommends that the Department of Health and Ageing work with AusAID to develop a mechanism for improving the participation of Australian experts in our international response.
2.4.7 A whole-of-government approach

The Review Panel stresses the importance of further developing a whole-of-government approach to managing HIV at both the domestic and the international levels. It is, however, apparent that a whole-of-government approach does not ‘just happen’ and that the structures, processes, incentives and resources must be there if progress is to be made.

As discussed in Section 2.2.5, HIV has become a chronic illness rather than a terminal one, and as a result its management has become increasingly complex. A number of submissions noted the success of the recently trialled ‘one stop shop’ system in high-caseload general practices in New South Wales.

Review participants mentioned a number of issues that require integrated and sophisticated management across a number of government and community sectors. Among these are the effects of proposed changes to pension benefits on income support for people living with HIV/AIDS and the effects changes to the Medical Benefits Schedule and the Pharmaceutical Benefits Schedule are having on access to treatments for these people.

Other important concerns for many participants are the increasing need for (and lack of availability of) mental health services and the supported accommodation and housing needs of people living with HIV/AIDS.

All the major submissions to the Review also noted the fact that many people who are infected with HIV or at risk of infection are ineligible for Medicare entitlements. This includes (with some exceptions) people who are not permanent residents of Australia and people who are in prison. Among the reasons for providing care to HIV-infected people who are currently ineligible for Medicare entitlements are the retardation of disease progression, and the consequent reduction in hospitalisation costs, and the reduction in the potential for further transmission of HIV.

**Recommendation 49**

The Review Panel recommends that task-focused, time-limited working groups—reporting to the HIV Committee—develop national approaches to complex cross-government questions such as:

- income support for people living with HIV/AIDS
- access to therapies
- models of care for people living with HIV/AIDS, including evaluation of the GP Enhanced Care Pilot Project in New South Wales
- mental illness services
- supported accommodation and housing for people living with HIV/AIDS
- Medicare ineligibility.
2.4.8 The need for a fifth National HIV/AIDS Strategy

The Review Panel strongly urges that a fifth National HIV/AIDS Strategy be developed—as a means of responding to the changing epidemic and to reinvigorate the national response.

As the foregoing recommendations demonstrate, it is the Review Panel’s view that the changes that are necessary are much more than simple refinements of the current Strategy. Significant improvements are needed—in the governance of the national response; in the breadth and intensity of the response at the national, state and territory, and community levels; and in our monitoring of and knowledge about the response itself and the contributions made by the key stakeholders.

Recommendation 50

The Review Panel recommends that a fifth National HIV/AIDS Strategy be developed to further develop and implement the foregoing recommendations. The Strategy should cover the three years from 2004–05 to 2006–07 and should be reviewed in mid-2006.
2.5 APPENDIX A THE REVIEW’S TERMS OF REFERENCE

The Minister for Health and Ageing approved the following Terms of Reference for the Review:

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 Inter-governmental 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...

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.
2.6 REFERENCES


Australian Research Centre in Sex, Health and Society 2002, HIV Futures 3—positive Australians on services, health and wellbeing, ARCSHS, Melbourne.

Department of Health and Ageing 2002, Return on Investment in Needle and Syringe Programs in Australia, Report prepared by Health Outcomes International in association with the National Centre in HIV Epidemiology and Clinical Research and Professor Michael Drummond, DoHA, Canberra.


REVIEW OF NATIONAL HEPATITIS C STRATEGY
1999–2000 TO 2003–04

THE ROAD NOT TAKEN

July 2002

Associate Professor Michael Levy
Professor Fran Baum
Professor Howard Thomas
Somewhere ages and ages hence:
Two roads diverged in a wood, and I—
I took the one less traveled by,
And that has made all the difference.
——Robert Frost
3.1 SUMMARY AND RECOMMENDATIONS

Hepatitis C poses a serious threat to population health in Australia. It is the most commonly diagnosed notifiable disease.

By the end of 2000 more than 160 000 diagnoses of hepatitis C infection had been reported. It is estimated that at the end of 2001 the number of people living with hepatitis C in Australia had risen to about 210 000. There were an estimated 16 000 new infections in 2001, compared with 11 000 in 1997. During the next 20 years, people with hepatitis C will experience increased morbidity and mortality as the epidemic unfolds.

The National Hepatitis C Strategy 1999–2000 to 2003–04 aims to:

♦ reduce the transmission of hepatitis C in Australia
♦ minimise the personal and social impacts of hepatitis C infection.

3.1.1 Main findings

This Review of Australia’s first National Hepatitis C Strategy 1999–2000 to 2003–04 found that the Strategy achieved two important goals:

♦ It has established a good foundation for action—a partnership between people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals, all of whom acknowledge the need to work in a collaborative, non-partisan manner with all other members of the partnership.

♦ It has contributed to an increased awareness of hepatitis C as a serious public health problem.

But the Strategy has not succeeded in controlling the hepatitis C epidemic in Australia. The urgency of this situation cannot be overstated.

The Review found a number of serious constraints to implementation of the Strategy:

♦ a focus on risk factors and individual behaviour change in the absence of a comparable focus on risk contexts and settings. A broader health-promotion approach would increase the effectiveness of future strategies

♦ lack of resources for implementation

♦ absence of an implementation plan and performance indicators for monitoring it

♦ governance structures that have not allowed hepatitis C to attract sufficient public attention or resources

♦ failure to grapple with the complexities of treatment and care

♦ erosion of harm reduction through drug laws and drug policies, despite advocacy against this from affected and professional communities
♦ inadequate research

♦ rudimentary surveillance

♦ lack of information about the economic impact of hepatitis C infection, especially in terms of the implications of the future cost of treatment and care to the community.

The focus on risk factors and individual behaviour change, rather than risk contexts and settings, and the need for a broader health-promotion approach

The Strategy is framed in the context of communicable diseases and focuses on:

♦ risk factors and specific circumstances of transmission, rather than specific population groups

♦ individual behaviour change, rather than the environments or settings that facilitate such change.

Despite modest achievements in health promotion under the Strategy, the overall level of activity is inadequate. There is little evidence of implementation focused on settings or local communities. Achievements in school-based education about hepatitis C are also limited. The Review received evidence suggesting that a stronger focus on the settings where people live and work would greatly improve the effectiveness of health-promotion efforts under the Strategy.

Lack of resources

The lack of resources to support implementation of the Strategy is a serious constraint.

Commonwealth program funding for hepatitis C has been limited. The states and territories and the non-government and community sector are largely dependent on limited resources from the Commonwealth to contribute to the development of an effective national response to the epidemic.

Hepatitis C is not one of the strategies or programs covered by the PHOFAs. These Agreements contribute to the national population health effort by providing broad-banded Commonwealth funding to state and territory governments to support nominated population health strategies and programs.

Absence of an implementation plan and performance indicators

The absence of a detailed implementation plan and performance indicators for monitoring it has seriously limited the Strategy’s effectiveness.

Governance structures

Existing governance structures have reinforced the position of hepatitis C as the ‘poor cousin’ of HIV. Since its inception the Hepatitis C Strategy has been closely aligned
with the HIV/AIDS infrastructure—for example, through ANCAHRD, IGCAHRD, the ‘partnership approach’, and research.

When hepatitis C began to emerge as a serious public health concern in Australia the HIV/AIDS infrastructure was well established. Hepatitis C was integrated into this infrastructure, first as a ‘related disease’, then achieving a degree of autonomy with the launch of the first National Hepatitis C Strategy. Hepatitis C is yet to achieve priority within this infrastructure, despite its greater impact in terms of the number of people affected and the projected cost burden relative to HIV/AIDS. Because of the dominance of the HIV/AIDS agenda, many opportunities for early, coordinated action to meet the challenges of hepatitis C have not been realised.

The partnerships established to support the Hepatitis C Strategy have not been entirely effective. This has compromised the taking of coherent national action.

Treatment and care

Despite the fact that hepatitis C treatment has been available for more than five years and overall sustained response rates are about 55 per cent, only an estimated 7 per cent of notified hepatitis C cases are being treated. Access to treatment and care is constrained by a number of factors:

- stringent eligibility criteria (S100)
- limited models of care
- the geographic and physical location of treatment services
- cultural and language barriers
- homelessness
- incarceration
- experiences of discrimination in health care settings.

Indications are that many people infected with the hepatitis C virus remain undiagnosed; being largely asymptomatic, they have not yet sought testing or treatment. Many people are not eligible for, choose not to have, or have not responded to treatment.

The affected community is not well informed about treatment and its relative efficacy. Further, the complex administration and toxicity of the treatments deter many people.

Erosion of harm reduction through drug laws and drug policies

Harm reduction is one of six essential components of the Strategy. The concept acknowledges that injecting drug use occurs and that associated harm, such as transmission of hepatitis C, can be reduced, both for individuals and for communities.
Current drug laws and drug policies have eroded the pragmatic philosophy of harm reduction, despite evidence of its effectiveness in reducing risk behaviour and preventing transmission of blood-borne viruses. Reform of these laws and policies is urgently needed if we are to reduce hepatitis C transmission among people who inject drugs. Governments need to reaffirm their commitment to harm reduction as a means of improving health, social and economic outcomes for individuals and the community.

With over 90 per cent of all new hepatitis C infections occurring among people who inject drugs, the continued use and injection of illicit drugs in Australia will have a powerful effect on the course of the hepatitis C epidemic.

Inadequate research and surveillance

The Strategy has not been adequately supported by research; nor has it been able to motivate a coherent research plan—through the NHMRC, ANCAHRD, or other means. The lack of a strong evidence base has hindered the effective implementation of the Strategy.

In terms of surveillance, a continuous flow of data to inform policy and programs at Commonwealth and state and territory levels is lacking. Hepatitis C surveillance is still based on prevalence data and this limits its utility in tracking the epidemic.

Lack of information about the economic impact of infection

There is not enough sharing of information between the agencies responsible for data collection, and there has been only limited research into the costs to the community of new hepatitis C treatments. The level of resourcing required at the Commonwealth and state and territory levels to reduce the future public health burden of hepatitis C is potentially great and definitely underestimated.

Expenditure on prevention of hepatitis C infection will be offset by future savings on end-stage treatment of hepatitis C–related liver disease and liver transplants.

3.1.2 Recommendations

The Review Team recommends as follows.

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<tr>
<th>Governance and partnerships</th>
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<tr>
<td>51. That the partnership approach be reaffirmed as essential to an effective national response to hepatitis C and that the non-government and community sector’s capacity to respond be enhanced, so that the sector can participate more effectively in the partnership.</td>
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<td>52. That new governance structures be developed to support the national response to hepatitis C.</td>
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</table>
53. That the states and territories review their governance structures for hepatitis C, so that they can develop equitable partnerships and match resources to identified needs.

54. That the National Public Health Partnership be expanded to include local government and non-government and community sector representation.

55. That the Commonwealth Parliamentary Liaison Group be revitalised and recognised as a very important element of the national response to hepatitis C.

Resources

56. That equitable, sustained funding be provided to develop and implement an effective response to hepatitis C in Australia at all levels—federal, state and territory, local government, and the non-government and community sector.

57. That the PHOFAs be used to ensure the allocation of a base level of resources and the setting of performance indicators for hepatitis C–related activity at the state and territory level.

**Discrimination and stigma**

58. That—in the light of the findings and recommendations of the November 2001 Anti-Discrimination Board of New South Wales enquiry into hepatitis C related discrimination—the Commonwealth and state and territory governments give priority to redressing hepatitis C–related discrimination in their jurisdictions.

59. That—on the basis of the experience of the New South Wales Hepatitis C Awareness Campaign—the Commonwealth support a national hepatitis C public awareness campaign to increase knowledge of and reduce the stigma associated with hepatitis C infection.

**Harm reduction**

60. That the following harm-reduction strategies be strongly supported in a range of settings:

- NSPs
- medical detoxification
- substitution therapies—including methadone and buprenorphine
- abstinence-based therapies
peer education programs.

Newer initiatives such as supervised injecting facilities, medically prescribed heroin and retractable needle and syringe technology should be rigorously evaluated before they are expanded.

61. That the recommendations of the Australian National Council on Drugs position paper on NSPs be implemented in all jurisdictions.

**Research**

62. That strategic and investigator-initiated research be recognised as fundamental to Australia’s response to hepatitis C and be equitably resourced.

63. That research be commissioned to:

- investigate the social and behavioural factors relating to hepatitis C transmission in a range of settings and contexts
- help develop and guide a broad range of hepatitis C prevention and health-promotion activities at all levels—federal, state and territory, local government, and the non-government and community sector
- explore the treatment, care and support needs of people living with hepatitis C
- investigate the reasons for the low uptake of treatments in Australia
- determine the future hepatitis C treatments load relative to the burden of disease
- investigate the economic impact of hepatitis C infection in Australia, to account for any changes in costs associated with new treatments
- develop and evaluate models of care for hepatitis C in the context of a systematic focus on health services.

64. That the hepatitis C research priorities of ANCAHRD be reviewed and that, if necessary, a new set of priorities be established to direct funding.

65. That the Clinical Trials and Research Committee be abolished and that hepatitis C research be incorporated in the Hepatitis C Committee’s brief.
66. That the Commonwealth and the states and territories renew their commitment to hepatitis C surveillance.

67. That the Commonwealth continue its support for the hepatitis C–related surveillance activities of the National Centre in HIV Epidemiology and Clinical Research.

68. That the Communicable Diseases Network Australia:
   ♦ conduct an evaluation of the Australian Hepatitis C Surveillance Strategy as a matter of priority, noting the drawbacks of a surveillance system based on prevalence data and the difficulty of obtaining accurate data on hepatitis C incidence
   ♦ provide to the existing Hepatitis C Committee, and its successor under a second National Hepatitis C Strategy, an annual report on the implementation of the Australian Hepatitis C Surveillance Strategy.

69. That the annual NSP survey be expanded to include adults and juveniles in custodial settings.

**Linkages and infrastructure**

70. That the Commonwealth lead a process, involving all key stakeholders, to review and create opportunities for more strategic and longer term links between the key national strategies referred to in Section 3.5 of the National Hepatitis C Strategy 1999–2000 to 2003–04.

**Priority health needs of Aboriginal and Torres Strait Islander peoples**

71. That there be greater emphasis on ‘front-end’ processes to guide the development of hepatitis C strategies, policies and research agendas, including requirements for appropriate engagement of affected communities, collaborative planning processes, and the use of Indigenous advisory and reference structures.
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<tr>
<td>72.</td>
<td>That the capacity of all health services be enhanced so that they can address hepatitis C prevention, education, treatment, care and support for Aboriginal and Torres Strait Islander peoples.</td>
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<td>73.</td>
<td>That culturally appropriate strategies and resources to prevent hepatitis C infection and its consequences be developed with and for Aboriginal and Torres Strait Islander peoples, through the state- and territory-based Aboriginal Health Partnerships and the Aboriginal community–controlled health sector.</td>
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<td><strong>People from culturally and linguistically diverse backgrounds</strong></td>
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<td>74.</td>
<td>That culturally appropriate strategies and resources to prevent hepatitis C infection and its consequences be developed with and for people from culturally and linguistically diverse backgrounds.</td>
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<td><strong>Treatment, care and support</strong></td>
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<td>75.</td>
<td>That awareness of the availability and efficacy of hepatitis C treatments be increased by targeted information provision through primary care physicians, specialist liver clinics and NSPs.</td>
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<td>76.</td>
<td>That a range of models of care for different settings—custodial, rural, and so on—be developed, implemented and evaluated.</td>
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<td>77.</td>
<td>That equitable funding be provided to develop models of comprehensive primary health care for communities bearing a high disease burden.</td>
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<td>78.</td>
<td>That an audit of actual treatment response rates become a standard reporting requirement for the states and territories under the Highly Specialised Drugs Program (S100).</td>
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<td>79.</td>
<td>That a national hepatitis C workforce program be developed in consultation with all key stakeholders. Affected communities should be engaged in the design and delivery of this program.</td>
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<td><strong>Rural and regional settings</strong></td>
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<td>80.</td>
<td>That people with hepatitis C or at risk of infection and living in rural, regional and remote areas of Australia have equitable access to hepatitis C–related education and prevention interventions, appropriate health care services that ensure a continuum of care, and innovative models of care.</td>
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<td><strong>Custodial settings</strong></td>
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<td>81.</td>
<td>That the lessons learnt from the application of harm-reduction strategies in custodial settings in other countries be explored for implementation in Australia.</td>
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82. That custodial staff be provided with training in relation to hepatitis C, in the context of occupational health and safety.

83. That a national policy on the provision of pharmacotherapies for illicit drug dependence in custodial settings be developed for all jurisdictions.

84. That broad support be given to initiatives designed to divert people who use illicit drugs away from incarceration and into non-custodial alternatives.

85. That nationally consistent standards for hepatitis C education and prevention be implemented in custodial settings.

**A second National Hepatitis C Strategy**

86. That—in close consultation with the people affected by hepatitis C, the community sector, the medical, health care, research and scientific communities, and all levels of government—the Commonwealth Department of Health and Ageing develop a second National Hepatitis C Strategy for the period 2004 to 2009, to further develop and implement the recommendations of this Review.

87. That a second National Hepatitis C Strategy:

- be framed in the context of communicable diseases but take a settings-based approach to health promotion

- be supported by dedicated funding, a detailed implementation plan with performance indicators, strong Commonwealth leadership, and new governance structures, including
  - establishment of new, separate Committees for Hepatitis C, HIV and Indigenous Australians’ Sexual Health, with a strong focus on implementation of the respective Strategies through setting their own work plans and incorporation of research and health promotion in their agendas. The new Hepatitis C Committee would comprise people with expertise in legislative and regulatory reform, health promotion, illicit drugs, disease prevention, the non-government and community sector and affected communities (including representatives from relevant peak bodies), public health, treatments (including specialist clinical services, general practice and allied health professions), Indigenous Australians’ health, research, workforce development, and custodial settings
  - establishment, by the new Hepatitis C Committee, of ad hoc working groups to deal with specific matters
  - establishment of a new Ministerial Advisory Committee for Hepatitis C, HIV and Sexual Health, comprising the chairs of the three new Committees and one overarching chairperson. This Committee would have a primary role in advocacy and securing sufficient resources to enable effective implementation of the Strategies and would be responsible for equity and collation of information, with minimal oversight of the work of the three Committees
- the new Ministerial Advisory Committee to forge strong links with national governance structures for illicit drugs
- reaffirm the six essential components of Australia’s response to hepatitis C—developing partnerships and involving affected communities, access and equity, harm reduction, health promotion, research and surveillance, and linked strategies and infrastructures
- be supported by appropriate legislative and regulatory frameworks, including drug law reform and anti-discrimination, which are necessary because of the magnitude of the epidemic
- be supported by evidence-based strategies developed in all jurisdictions
- take account of the changes in diagnostics, treatment and care, and workforce development that have occurred during the term of the first Strategy
- designate clinical outcome indicators for hepatitis C
- be monitored and evaluated in all jurisdictions
- be subject to an independent, external mid-term review.

88. That monitoring the impact of hepatitis C in the Asia–Pacific region and international assistance and cooperation in respect of hepatitis C not be a primary consideration for a second National Hepatitis C Strategy.

3.1.3 Conclusion
A second National Hepatitis C Strategy is essential for dealing with the hepatitis C epidemic in Australia.

The Strategy must be supported by effective partnerships, strong governance structures, equitable resource allocation, legislative and regulatory reform, committed professional action, and community advocacy. Otherwise, too many people will continue to become infected, and Australia will not be able to meet the substantial costs of treating and caring for the hepatitis C–affected community in 15 to 20 years’ time.

With hepatitis C, Australia has an opportunity to seize international recognition for its strong political leadership and innovation—just as it did in a previous century with HIV/AIDS.
3.2 THE REVIEW PROCESS

3.2.1 Background

On 28 March 2002 the Commonwealth Minister for Health and Ageing, Senator the Hon Kay Patterson, approved the structure and Terms of Reference for the review of the first National Hepatitis C Strategy. The Review is part of a larger process that also involves reviews of the National HIV/AIDS Strategy and the National Centres in HIV Research.

This Review of the Hepatitis C Strategy has two broad aims:

♦ to assess the extent to which the Strategy’s recommendations and guiding principles have been implemented or adopted and their appropriateness

♦ to provide the Minister for Health and Ageing with advice that will inform the next phase of Australia’s response to the hepatitis C epidemic.

The Review’s full Terms of Reference are provided in Section 3.13 (Appendix A).

3.2.2 The Review Team

Membership of the Review Team was as follows:

♦ Associate Professor Michael Levy—Director, Population Health, Corrections Health Service, New South Wales (Chair)

♦ Professor Fran Baum—Head, Department of Public Health, Flinders University, South Australia

♦ Professor Howard Thomas—Head, Department of Medicine A, Faculty of Medicine, Imperial College of Science, Technology and Medicine, St Mary’s Hospital, London.

Secretariat services were provided by:

♦ Ms Michaela Coleborne—Assistant Director, Hepatitis C Section, Commonwealth Department of Health and Ageing

♦ Ms Lorraine Breust—Director, Hepatitis C Section, Commonwealth Department of Health and Ageing.

The Review Team acknowledges their devoted and well-informed support.

The Review Team met from 11 to 14 June 2002 and again on 4 July. Professor Howard Thomas was not able to attend the 4 July meeting.
3.2.3 Submissions and presentations

On 16 April 2002 the Population Health Division of the Department of Health and Ageing contacted key stakeholders and interested parties, inviting them to make written submissions to the Review by Friday 24 May. Forty-five written submissions were received and considered by the Review Team; the submitters are listed in Section 3.14 (Appendix B).

Between 11 and 14 June the Review heard 10 oral presentations (see Section 3.15 (Appendix C)). Following the presentations, the Chair of the Review Team interviewed key informants.
3.3 THE STRATEGY’S EFFECTIVENESS

The first term of reference requires the review team to:

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.

3.3.1 The Strategy’s position in a broader communicable diseases context

Before the first National Hepatitis C Strategy was developed, three options for continuing Australia’s response to hepatitis C were canvassed: separate hepatitis C and HIV/AIDS strategies; further development of the ‘HIV/AIDS and related diseases’ approach; and a communicable diseases framework with specific sub-strategies (Department of Health and Aged Care 1999). The first option was adopted. The rationale for a separate strategy was clear: the hepatitis C epidemic was very different from other epidemics, including HIV; it required a singular focus and a corresponding level of commitment. Past success with other disease-specific strategies lent weight to this approach.

People affected by hepatitis C, the community sector, the medical, health care, research and scientific communities, and all levels of government welcomed the launch of the Strategy in June 2000. It was the first dedicated National Hepatitis C Strategy for Australia—and possibly the first such strategy in the world.

provides a firm platform from which to launch efforts to address the serious impacts of hepatitis C.

The Strategy is framed in the context of communicable diseases, with a focus on:

♦ risk factors and specific circumstances of transmission, rather than on specific population groups

♦ individual behaviour change, rather than environments or settings that facilitate such change.

It also emphasises the need for improved access to health care services for Aboriginal and Torres Strait Islander communities, people in rural and remote areas, and people from other cultural groups.

The Review Team found that a dedicated Strategy for hepatitis C has:

♦ increased the profile of hepatitis C and put it firmly on the national health agenda

♦ allowed a greater focus on specific aspects of hepatitis C, among them barriers to reducing transmission and minimising the personal and social impacts of infection

♦ enabled stronger involvement of affected communities and other key stakeholders in the development and implementation of a national response.

But the Review Team also found limitations to the Strategy:

♦ lack of coordination with other strategies, including those framed in the context of communicable diseases

♦ lack of resources for implementation

♦ the focus on individual behaviour change, rather than a setting-based approach.3

3 In this context, a setting is ‘a place comprised of a location and its social context in which people interact daily. Examples of settings include schools, workplaces, hospitals …’ (WHO 2000).

3.3.2 The degree to which the Strategy has been implemented

The Review Team found that the Strategy has been implemented to some degree at the national level and in each state and territory. Various factors have hindered implementation, among them lack of leadership, lack of resources, and insufficient knowledge of the relative burden of disease.

Leadership

The Review Team concluded that there remains considerable scope for developing strong national leadership in relation to hepatitis C, in a manner similar to the international leadership role Australia has played in the HIV/AIDS epidemic.
Resources

The lack of resources to support implementation of the Strategy was widely acknowledged in submissions to the Review. The states and territories and the non-government and community sector rely on limited Commonwealth resources to develop and implement programs to support the Strategy.

The Review Team received several submissions critical of the Retractable Needle and Syringe Technology Initiative announced as part of the 2002 Federal Budget. This initiative may affect hepatitis C control. The Team hopes that, at the end of the phase 1 implementation plan for the initiative, a portion of the allocated funding will be made available for specific hepatitis C–related initiatives.

The burden of disease

On the basis of submissions received, it is not clear whether state and territory action in relation to hepatitis C has been in response to proven need, perceived need or non-strategic expediency. The Review Team acknowledges that some very positive moves have been made at the state and territory level—through the formation of committees, assessment of local needs, development of specific strategies, and local partnerships with groups representing affected communities. It did, however, find significant variations in the level of activity.

Although the burden of disease may vary between states and territories, the Review Team found little information to support this proposition. It is appropriate that states and territories match their management efforts to the magnitude of the problem; it is also essential that national surveillance form the evidence base for these efforts.

3.3.3 Developing partnerships and involving affected communities

The partnership approach is a fundamental principle of population health policy. It involves collaboration between affected communities and the medical, health care, research and scientific communities in the development and implementation of effective responses to health problems. The Strategy supports this approach and states that the involvement of affected communities is critical.

The Review Team found that, under the auspices of the Strategy, partnerships have been developed and affected communities have been engaged to some extent. More effort is now needed to:

♦ develop equitable partnerships, where resources are matched to identified need
♦ encourage more effective collaboration between partners at all levels
♦ clarify the roles of the various partners
♦ increase the affected communities’ involvement in the development and implementation of programs and services.
3.3.4 Access and equity

The Strategy states that access and equity are achieved when programs and services are designed in such a way as to accommodate the diverse cultural, geographic, social and economic circumstances of people with hepatitis C, including:

♦ people who inject drugs
♦ people in custodial settings
♦ people living in rural and regional Australia
♦ people from culturally and linguistically diverse backgrounds
♦ Aboriginal and Torres Strait Islander peoples.

The Review Team found negligible achievements for access and equity through the Strategy.

People who inject drugs

Access to hepatitis C–related programs and services by people who inject drugs is reduced by:

♦ stigmatisation of injecting drug use, leading to discrimination, especially in health care settings
♦ criminalisation of injecting drug use
♦ lack of government commitment to providing health and drug treatment services for people who inject drugs.

In the Review Team’s view, this is unacceptable.

There is growing recognition that criminalisation of injecting drug use has not been effective in controlling the hepatitis C epidemic. Rather, it has contributed to increased transmission rates among people who inject drugs. For example, self-administration (or ‘use’) of a prohibited drug remains an offence in New South Wales; this discourages people who inject drugs from attending NSPs and carrying sterile injecting equipment, increasing the likelihood that they will share injecting equipment. Illicit drug use should be treated as a health and social concern, not a question of criminal justice. Fundamental to the success of Australia’s approach to HIV was the decriminalisation of homosexuality. Reform of drug laws and policies is now needed to reduce hepatitis C transmission. This includes:

♦ diversion from custody for drug-related offences
♦ harm reduction in custodial settings
♦ introduction of a regulatory regime for the illicit drug market in Australia—similar to that which exists for tobacco and alcohol.
The Review Team considers that people who inject drugs have a right to the same standard of health care as citizens in the general community. Lack of government commitment to confronting this issue compounds the stigma associated with injecting drug use.

Many submissions to the Review expressed concern about government resources being used to develop retractable injecting equipment when there would appear to be little evidence supporting the need for, effectiveness of or likely uptake of such equipment in Australia.

**People in custodial settings**

The first National Hepatitis C Strategy acknowledges that a history of incarceration is a potent risk factor for hepatitis C transmission because of the high prevalence of the disease in custodial populations.

The Review Team found, however, that, with two notable exceptions, prison health practices in the states and territories have remained essentially unchanged during the term of the Strategy. The exceptions are South Australia, which has introduced methadone maintenance for people in custodial settings, and Queensland, which has initiated a trial of methadone prescribing for people in custodial settings. It is uncertain what role the Strategy has played in these two initiatives.

A number of basic facts are relevant in this regard:

- There are too many people in custody, and many of them are there for drug-related offences.
- Aboriginal and Torres Strait Islander peoples are disproportionately represented in custodial settings in every Australian jurisdiction.
- There are no accepted national standards for health care provision in custodial settings.
- People in custody are entitled to the standard of health care and the therapeutic options that are available to citizens in the general community.
- There are inconsistencies in the jurisdictions’ implementation of harm reduction.
- The custodial system cannot prevent drug use. Harm reduction is the preferred approach to reducing the risk of transmission of blood-borne viruses in custodial settings.

**People living in rural and regional Australia**

The Review found little evidence of activity designed to reduce hepatitis C transmission and the personal and social impacts of infection in rural and regional Australia. Submissions noted the following problems:

- limited access to treatment and related services
difficulties complying with complex diagnostic and treatment regimes

♦ lack of confidentiality

♦ discrimination in health care settings

♦ lack of access to NSPs and associated harm-reduction measures

♦ lack of support services for people with hepatitis C.

See also Section 3.6.

**People from culturally and linguistically diverse backgrounds**

The Review Team found some evidence of hepatitis C–related activity aimed at meeting the information and education needs of people from culturally and linguistically diverse backgrounds. This included Commonwealth funding for two national projects and several state and territory projects initiated under the Strategy. But this level of activity is inadequate. Submissions noted the following:

♦ lack of confidentiality

♦ the language and appropriateness of information and education materials

♦ literacy in languages other than English

♦ cultural attitudes to injecting drug use and the sharing of injecting equipment.

The Review also received submissions commenting on the situation of asylum seekers detained in Australia with regard to hepatitis C diagnosis, treatment and care. In the Review Team’s opinion, asylum seekers should be entitled to the standard of health care that is available to citizens in the general community.

**Aboriginal and Torres Strait Islander peoples**

The discrimination, stigma and disadvantage experienced by Aboriginal and Torres Strait Islander peoples act to limit their access to hepatitis C–related programs and services. Section 3.3.10 discusses in more detail the health needs of Aboriginal and Torres Strait Islander peoples.

**Summary**

The Review found little to demonstrate that access and equity are being effectively dealt with through the Strategy. Structural inequities in health generally are replicated with hepatitis C. The affected communities are very marginalised, experiencing cultural, social and economic disadvantage. This situation is not unique to hepatitis C: most diseases thrive in such circumstances.

See Section 3.5 for a discussion of related matters such as workforce development, access to and uptake of treatments, and discrimination.
3.3.5 Harm reduction

Harm reduction is one of six essential components of the first National Hepatitis C Strategy, which asserts that governments have a responsibility to develop and implement population health measures designed to reduce drug-related harm, for both individuals and communities. Harm reduction includes peer-based initiatives, information provision, NSPs, and the creation of safe environments.

Many submissions to the Review argued that harm reduction continues to be highly effective in reducing risk behaviour and the transmission of blood-borne viruses, especially among people who inject drugs. This is supported by recent research commissioned by the Commonwealth (Department of Health and Ageing 2002b). A recent position paper on NSPs lends further weight to the argument for a harm-reduction approach to preventing hepatitis C transmission (Australian National Council on Drugs 2001a).

The Review Team is aware of modest achievements for harm reduction during the term of the Strategy:

♦ Commonwealth and state and territory funding for some peer-based initiatives
♦ funding for some NSP-specific project activity at the Commonwealth and state and territory levels
♦ commissioned research supporting NSPs as an effective harm-reduction intervention
♦ continued funding for NSPs through the states and territories.

The Review Team notes, however, that most of this activity has not been funded through hepatitis C programs.

Despite evidence of the effectiveness of harm-reduction measures in reducing risk behaviour and preventing transmission of blood-borne viruses, the Review Team found that support for harm reduction in Australia is constantly under pressure. Peer-based initiatives receive inadequate funding and operate in hostile environments. There are increased expectations that NSPs will be able to provide a range of additional services for people with hepatitis C, without additional funding. Training for the NSP workforce has not kept pace with the increasing demands on the services. Further, there is no broader strategy to establish harm reduction as an acceptable and normal practice in communities and institutions.

At the federal level, government policy in relation to harm reduction has changed in the last few years. The language has become clouded. For example, the National Drug Strategic Framework 1998–99 to 2002–03 positioned ‘harm minimisation’ as an umbrella term, supported by three distinct components:

♦ harm reduction
♦ supply reduction
♦ demand reduction.

The National Illicit Drugs Action Plan, which comes under the Framework, refers only to supply-reduction and demand-reduction strategies.

As a concept, harm reduction acknowledges that injecting drug use occurs and that associated harm, such as transmission of hepatitis C, can be reduced, for both individuals and communities. This appears to be at odds with the supply-reduction and demand-reduction approaches to illicit drug use, which are abstinence-based—that is, the ‘zero tolerance’ idea. The Review Team considers that incorporating these three components under one umbrella has created confusion, undermining Australia’s pragmatic approach to hepatitis C education and prevention efforts.

As Puplick C. (2001, p. 202) argues,

Attitudes of moral disapproval, and the general failure of most political leaders to face up squarely to the extent of unlawful drug use, continue to bedevil the adoption of sound, evidence-based approaches to confronting the hepatitis C epidemic and its associated manifestations of discrimination.

An earlier report on Australia’s response to hepatitis C (Department of Health and Aged Care 1999) stated that the decreased political commitment to harm minimisation as an effective strategy in relation to illicit drugs and blood-borne viruses suggested an unwillingness to implement more effective approaches in this area. The Review Team found that little progress has been made since that report: governments need to reaffirm their commitment to harm reduction as a means of improving health, social and economic outcomes for individuals and the community.

### 3.3.6 Health promotion

The principles and strategies of the WHO’s Ottawa Charter for Health Promotion⁴ were the basis for the National Hepatitis C Strategy, which supported the following measures under the banner of health promotion:

♦ peer education

♦ public education and campaigns

♦ professional education and training

♦ self-directed learning

♦ school-based education

♦ development of health-promoting policies

♦ a focus on the settings in which people live and work, to make the settings more supportive of health.

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⁴ The Charter is available at http://www.who.int/hpr/archive/docs/ottawa.html.
The Review Team endorses the use of the Ottawa Charter framework, and it found some modest achievements for health-promotion strategies initiated during the life of the Strategy, including:

♦ peer-based education through drug user organisations

♦ a public awareness campaign in New South Wales

♦ a national hepatitis C campaign targeting people who inject drugs

♦ some workforce development
  – education and training for GPs, nurses, ambulance workers, dentists and dental workers
  – distance-based learning undertaken by community-based organisations and professional associations
  – a national hepatitis C educators workshop
  – professional development for teachers

♦ new policies and resources to promote health maintenance and self-care for people with hepatitis C

♦ state and territory support for projects designed to meet local needs.

Some of these strategies have been evaluated and were found to have had varying degrees of success, but the Review Team is not satisfied with the overall level of health-promotion activity to support the Strategy.

Submissions to the Review provided little evidence of:

♦ achievement of policy change to create supportive environments—the approach to health promotion favoured by the Ottawa Charter

♦ implementation focused on settings or local communities

♦ achievements in school-based education about hepatitis C—apart from some nationally funded activities that have taken place in conjunction with HIV programs.

Workforce development has been limited, albeit clearly defined in response to identified needs. Levels of professional education and training being undertaken at the national and state and territory levels are inadequate. Undergraduate training for medical and nursing students needs to be strengthened. Given the projected burden of hepatitis C–related disease, and the identified need to expand service delivery and models of care, it is critical that more resources are allocated to professional education and training at all levels.

The Review Team found that there is a high level of support for a national hepatitis C public awareness campaign to increase knowledge of and reduce the stigma associated
with hepatitis C infection, based on the success of the New South Wales Hepatitis C Awareness Campaign.

### 3.3.7 Research

Although hepatitis C research is being assessed in the Strategy Research Review (covering both HIV/AIDS and hepatitis C), it remains highly relevant for this Review of the National Hepatitis C Strategy, which states that research is 'crucial to providing an evidence base for the development of public policy and programs, clinical treatments and therapies, and services that are compatible with the evolving needs of people affected by hepatitis C'.

The Review Team notes that in August 2000 the Hepatitis C Committee of ANCAHRD developed a set of 15 hepatitis C research priorities, using the priority areas in the Strategy. Some priorities related to virological, clinical and epidemiological research; it was considered that others were best addressed through social research. This question of hepatitis C research priorities was highlighted by a workshop held in October 2001, organised by the ANCAHRD Clinical Trials and Research Committee and the Hepatitis C Committee. The Review Team could not determine whether these priorities have influenced research-funding decisions and processes. Submissions to the Review expressed dissatisfaction with Clinical Trials and Research Committee and sought clarification of priority-setting processes and decision-making, advisory and reporting structures for hepatitis C research.

In the Review Team’s opinion, the Strategy has not been adequately supported by relevant research, nor has it been able to motivate a coherent research plan, through the NHMRC, ANCAHRD or other means. Lack of a strong evidence base has hindered the effective implementation of the Strategy.

A recurrent theme in submissions to the Review was the inadequacy of Commonwealth program funding for hepatitis C research. The Review Team concedes that funds for research from the Population Health Division of the Department of Health and Ageing have been limited and that additional NHMRC funds have not been deployed to support hepatitis C strategy research. The Review Team notes that the Strategy Research Review makes recommendations for different systems of funding to be developed through the Australian Research Council and the NHMRC. While such systems are being developed, funds could be made available to support strategic research, including research into affected populations and the settings in which hepatitis C is transmitted.

Some hepatitis C–related research has been conducted through the National Centres in HIV Research as a result of specific negotiations with the Department. The main branches of research contributing to the population health effort to address hepatitis C are epidemiology, basic scientific research, virology, clinical research, and social and behavioural research.

There is a strong focus on HIV research through the National Centres, and this has created a vacuum in hepatitis C research. Australia’s success in managing the HIV epidemic has been attributed to the robust evidence base provided by research: this approach should also be central to the strategic response to hepatitis C. Research
effort should focus not only on the National Centres but also on other researchers and other institutions. The National Centres could play a role in mentoring and supporting research in other institutions. The alliance between the National Centre in HIV Epidemiology and Clinical Research and the Australian Liver Association is promising but requires substantial funding and long-term commitment—a lesson learnt from Australia’s response to HIV.

Submissions to the Review criticised hepatitis C social and behavioural research for not being responsive to conditions ‘on the ground’. This criticism would appear to apply particularly to investigator-initiated research. Another criticism levelled at research is that it is not always conducted in the true spirit of collaboration, contrary to the philosophy espoused by the Strategy.

In a social research needs analysis conducted in 2001, certain groups in the community sector—defined both geographically and in terms of injecting drug use—stated that they are experiencing ‘research fatigue’ (National Centre in HIV Social Research 2002). The available resources limit the community sector’s capacity to become involved in or initiate research projects. This claim is supported by an analysis of submissions from the community sector to the Review.

The Review Team acknowledges the usefulness of a research project into the disposal of injecting equipment, which was commissioned by AIVL (the Australian Injecting and Illicit Drug Users League) and published in 2002 with Commonwealth funding. It also notes a study into the structural determinants of youth drug use, commissioned by the Australian National Council on Drugs and published in 2001 (Australian National Council on Drugs 2001b).

On the basis of submissions received, the Review Team found that hepatitis C research needs to expand our knowledge of:

♦ the hepatitis C virus and mechanisms of viral clearance
♦ effective strategies to reduce hepatitis C transmission in the community
♦ current best practice in conventional treatments and the clinical outcomes of those treatments
♦ treatment efficacy
♦ health maintenance and the care and support needs of people affected by hepatitis C
♦ effective strategies to prevent discrimination and reduce stigma and isolation
♦ social and behavioural aspects of hepatitis C infection.
3.3.8 Surveillance

The Australian Hepatitis C Surveillance Strategy was endorsed in 1999 by the Communicable Diseases Network of Australia and New Zealand (now the Communicable Diseases Network Australia). It made provision for improved notification protocols and improved mechanisms for monitoring and surveillance of hepatitis C in Australia.

The Review Team found modest achievements for hepatitis C surveillance during the life of the Strategy.

During the year 2000, 20,926 hepatitis C infections were reported, bringing the total number of notified cases of hepatitis C in Australia to more than 160,000 since antibody testing became available in 1990 (National Centre in HIV Epidemiology and Clinical Research 2001). The Review Team notes, however, the likelihood that many people with hepatitis C infection remain undiagnosed. It has been estimated that there may be up to 16,000 new infections each year and up to 250,000 people living with hepatitis C antibodies (Hepatitis C Virus Projections Working Group 2002).

It took many years to establish a reliable system of HIV surveillance; hepatitis C is only just starting out on this road. Lack of funding is one factor affecting the development of an effective hepatitis C surveillance system.

The Review Team considers that the main problem with hepatitis C surveillance is that it is based on prevalence data. To refine prevalence data as a proxy for incident cases, a new system is being trialled in all states and territories except Queensland: a new diagnosis is the proxy for an incident case. This system mirrors the evolution of the HIV surveillance system, but it needs increased resources to be more effective.

The National Centre in HIV Epidemiology and Clinical Research has the mandate for HIV surveillance, and this has contributed to the success of the HIV response. The Review Team suggests that the Centre develop specific competence in hepatitis C surveillance.

The Review Team also suggests that the states and territories allocate a set percentage of funding to hepatitis C surveillance.

The efforts made thus far to identify new infections are commendable, but they must be sustained if the evolution and impact of the hepatitis C epidemic are to be properly assessed.

See also Section 3.7.

3.3.9 Linked strategies and infrastructures

The National Hepatitis C Strategy states that effective implementation of the Strategy demands coordination with other national population health initiatives that have a bearing on the health and wellbeing of people affected by hepatitis C. In this regard, it notes the following:
♦ Links and opportunities for joint efforts should be explored with other strategies, policies and programs, to allow better coordination and reduced duplication of effort.

♦ State and territory hepatitis C strategies and action plans should be consistent with the objectives and priority areas identified in the National Strategy.

♦ Better coordination is needed across the community and other non-government sectors, to maximise opportunities.

♦ The National Public Health Partnership is an important mechanism for coordinating efforts across the spectrum of population health activity in Australia.

The Review Team did not find enough evidence of effective links with other strategies, policies and programs at the Commonwealth and state and territory levels. It found as follows:

♦ The Strategy does not specify clearly how these links are to be made. This has led to confusion about roles, responsibilities, advisory structures and funding arrangements.

♦ Resources to make the links are lacking.

♦ There is no well-thought-out implementation plan to fashion the links.

On a positive note, the Review Team sees the endorsement, by all the states and territories, of the Strategy by December 2000 as a significant achievement. Further, many states and territories have developed hepatitis C–specific strategies, adapting and implementing a range of programs supporting the National Strategy at a local level. This activity is praiseworthy, but it is not in proportion to the magnitude of the problem.

The Review Team supports IGCAHRD in its role as the principal forum for information exchange in relation to hepatitis C policy between the states and territories, the Commonwealth and peak community-based organisations. It also supports the National Public Health Partnership in its role of coordinating efforts across the spectrum of population health activity in Australia.

See also Section 3.9.

3.3.10 Priority health needs of Aboriginal and Torres Strait Islander peoples

The National Hepatitis C Strategy emphasises the need for:

♦ improved access to health care services for Aboriginal and Torres Strait Islander peoples
increased use of the population health networks that exist for Aboriginal and Torres Strait Islander peoples and the establishment of partnerships across different sectors

development of innovative responses that are culturally appropriate to the specific circumstances of Aboriginal and Torres Strait Islander peoples.

The Strategy recognises that links are needed with Aboriginal and Torres Strait Islander health policy and program frameworks such as the National Indigenous Australians’ Sexual Health Strategy, the Aboriginal Health Framework Agreements, and the National Aboriginal Health Strategy. It also states that the discrimination, stigma and disadvantage experienced by Aboriginal and Torres Strait Islander peoples act to limit their access to primary health care services. Further, it acknowledges the critical importance of Aboriginal and Torres Strait Islander primary health care services.

The Review Team found that the priority health needs of Aboriginal and Torres Strait Islander peoples in relation to hepatitis C are complex and generally not well described. Hepatitis C is but one factor contributing to the heavy disease burden among this population group. Despite several important projects funded during the term of the Strategy, there has not been a comprehensive response. One significant achievement, however, is the growing recognition of hepatitis C’s impact and the risks associated with unsafe injecting practices.

Sentinel surveillance of hepatitis C infection among people attending NSPs has detected an increasing proportion of Aboriginal and Torres Strait Islander participants, but there is no indication of differences or trends in prevalence according to Indigenous status. Rates of hepatitis C infection among Indigenous Australians attending NSPs—in particular among those with a relatively short history of injecting—suggest continuing risk behaviour. This contrasts with the prevalence rates for HIV infection monitored through the same surveys.

Submissions to the Review claimed that Aboriginal and Torres Strait Islander peoples who inject drugs may be at increased risk of hepatitis C infection because of the limited availability and use of harm-reduction interventions. Research in Western Australia suggests that there may be more Indigenous Australians injecting drugs than has been previously thought. We have much to learn about drug-injecting practices and rates of hepatitis C infection in this population group.

Aboriginal and Torres Strait Islander peoples are over-represented in custodial settings, placing them at increased risk of hepatitis C infection (Australian Institute of Health and Welfare 2001). Despite this, custodial settings offer opportunities to engage people at risk. Some research is being done in custodial settings in New South Wales to assist policy development in this regard.

The Review Team notes that the Aboriginal Health Framework Agreements have strengthened the capacity for collaborative action to implement the Strategy, but such action remains limited. Concerns have been expressed within the Aboriginal community–controlled health sector about the need for better accountability measures under the Framework Agreements and the PHOFAs.
In the Review Team’s opinion, the Aboriginal community–controlled health sector’s capacity to give priority to hepatitis C is still limited. The sector needs significant augmentation if it is to respond adequately to the epidemic. In 15 to 20 years’ time—when hepatitis C morbidity and mortality rates are likely to be high among Aboriginal and Torres Strait Islander peoples—the sector will have great difficulty coping with the demand for services.

The Review Team points out that limited data exists on the clinical outcomes for Aboriginal and Torres Strait Islander peoples affected by hepatitis C.

Submissions to the Review discussed many other matters, among them the limited evidence base and the difficulties this creates for future planning; privacy and ownership and control of information; research ethics and the ownership of research findings; access to treatment; and confounding factors such as co-infection, diabetes, and alcohol and other drug dependency problems.

Given the over-representation of Aboriginal and Torres Strait Islander peoples in custodial settings and the lack of services to meet their needs, the future impact of hepatitis C–related disease in this population group is likely to be profound.

See also Sections 3.6, 3.9 and 3.12.
3.4 THE PARTNERSHIP APPROACH

The second term of reference requires the Review Team to:

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.

The first National Hepatitis C Strategy states,

Partnership is a fundamental principle of successful population health policy. It recognises that collaborative efforts—by all levels of government; community organisations; the medical, health care, research and scientific communities; and people affected by hepatitis C—are required for an effective national response to hepatitis C and it is based on a commitment to consultation and joint decision making in all aspects of the response.

The Review Team found that the partnerships established to support the Strategy have not been very effective and that this has compromised the delivery of a coherent national Strategy. The partnerships need to be clarified, and they need to be relevant and stronger.

3.4.1 Commonwealth, state and territory and local governments

Governance problems affecting the partnership approach at the Commonwealth and state and territory levels in relation to hepatitis C and illicit drugs were a recurrent theme in submissions to the Review. Many submissions cited difficulties working within structures that have evolved from the HIV response. Alternative structures were suggested for the Review Team’s consideration.

The Review Team considers that revised structures at the Commonwealth and state and territory levels are needed, for two main reasons:

♦ to foster an independent identity and a specific modus operandi for hepatitis C

♦ to give greater emphasis to equitable resourcing for hepatitis C in the context of the total population’s health care needs.

Establishment of a dedicated Hepatitis C Section (containing staff with expertise in hepatitis C) within the Department of Health and Ageing has enhanced the partnership approach under the Strategy. Submissions to the Review supported the Section’s continuance, with additional resources. The Review Team found, however, that
relationships between this Section and other areas of the Department need to be clarified.

Although the Review Team supports the role of the National Public Health Partnership in coordinating efforts across the spectrum of population health activity in Australia, it notes that the Partnership does not have representation from local government or from peak bodies in the non-government and community sector.

The PHOFAs could be used to develop the Commonwealth–State–Territory partnership. The Review Team does not want to be more specific on this, but it recognises opportunities the Agreements could present for hepatitis C.

The Review received few submissions commenting on the role of local government in responding to hepatitis C, so the Team was not able to make an assessment of the partnership approach in this context.

See also Sections 3.3 and 3.9.

3.4.2 The Australian National Council on AIDS, Hepatitis C and Related Diseases and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases

The ANCAHRD Hepatitis C Committee is committed to the partnership approach and has a good, albeit brief, track record with hepatitis C at the national level. The Review Team found, however, that at the level of ANCAHRD hepatitis C has been denied an equitable hearing in comparison with other population health matters. Those with an interest in hepatitis C appear to have less influence in setting the agenda at this level. Complex and often tenuous inter-agency relationships have been used as an excuse for abrogating responsibility for hepatitis C. In the Review Team’s opinion, hepatitis C deserves a better hearing given the magnitude of the problem.

The role of the Clinical Trials and Research Committee is discussed in Section 3.3.7.

The Review Team found no evidence of an effective partnership between ANCAHRD, its sub-committees and the ANCD. Submissions expressed concern that the ANCD’s general approach to illicit drugs inhibits an effective national response to hepatitis C.

Submissions to the Review supported IGCAHRD as critical to the implementation of the Strategy. The Review Team found that IGCAHRD has the potential to add greater value to a strategic national response to hepatitis C.

3.4.3 Research, medical, scientific and health care professionals

The first National Hepatitis C Strategy states,

Australia’s research and scientific communities play an essential role in reducing discrimination, reducing the transmission of hepatitis C, and providing treatment and care and support. The contribution of people working in these areas should be maximised through intersectoral cooperation at all levels.
It further states,

- the research–practice interrelationship should be fostered through sustainable mechanisms;
- multi-disciplinary collaboration is encouraged;
- community involvement is necessary in setting the research agenda, in the design and execution of research, and in disseminating the results.

The Review Team found some evidence of effective partnerships between researchers, health professionals and the community sector, but it questions their sustainability given limited resources. Submissions to the Review suggested that the community sector is not always sufficiently involved in research efforts (see Section 3.3.7). Increased commitment from all partners is needed to foster collaboration.

Submissions to the Review also noted that much work is yet to be done to develop partnerships with medical, scientific and health care professionals. The magnitude of the problem, the dearth of trained staff, and documented discrimination in health care settings demonstrate the need to improve partnerships. They also highlight the need to integrate and amplify service delivery more effectively.

The Review Team considered a variety of models that need to be explored, tested and commented on in terms of partnerships and service delivery:

- health services research to look at coordinated and shared care
- managed clinical networks
- development of existing community health infrastructure
- opportunities to use the Enhanced Primary Care item under Medicare.

The Review Team notes that some of these matters were raised in the Strategy.

### 3.4.4 The non-government and community sector

The Review Team found that the non-government and community sector has been engaged to some extent under the auspices of the Strategy and has played an important role in responding to hepatitis C at the Commonwealth and state and territory levels. This sector’s capacity for such activity is limited by available funds and competing demands. Key areas of the sector—some state- and territory-based drug user organisations and hepatitis C councils—remain unfunded, despite Commonwealth funding to the states and territories for education and prevention activities. This situation is unacceptable: there should be greater involvement of affected communities at all levels of the response to hepatitis C.
3.5 TREATMENT, HEALTH MAINTENANCE, CARE AND SUPPORT

The third term of reference requires the Review Team to:

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.

3.5.1 Clinical outcomes for hepatitis C

During the 1970s and 1980s, 1 to 2 per cent of people in Australia who received blood transfusions developed hepatitis but tested negative for hepatitis A and B. Following the discovery of the hepatitis C virus in 1989 and the development of an antibody test for its detection in 1990, it was found that approximately 90 per cent of these non-A, non-B post-transfusion hepatitis cases were caused by the hepatitis C virus (National Health and Medical Research Centre 1994).

Australians have been exposed to hepatitis C for 30 years. As a consequence, in the coming decade an increasing number of people will be experiencing morbidity and mortality consistent with longstanding infection.

Since the first National Hepatitis C Strategy was conceived and endorsed, the clinical outcomes for hepatitis C have improved. Nevertheless, hepatitis C is not a mild, innocuous disease: 20 per cent of people who develop chronic infection will progress to cirrhosis. Several submissions pointed out that we have over-emphasised the mortality and under-emphasised the morbidity associated with chronic hepatitis C infection.

The Review Team notes evidence that sustained response rates have increased to 55 per cent overall with combination therapy, indicating that the efficacy of current hepatitis C treatments is improving. It remains limited, however. Through the Highly Specialised Drugs Program, combination therapy with α-interferon and ribavirin provides a sustained viral response rate of 40 per cent overall; that is, in 40 per cent of treated patients, hepatitis C RNA remains undetectable by polymerase chain reaction testing. Patients with hepatitis C genotypes 2 or 3 can expect a 60 to 70 per cent sustained response rate.

The Review Team notes, too, that research using self-perceived health measures and more specific brain metabolism studies suggest that hepatitis C has particular effects on the brain, with links to depression (Foster et al. 1998; Forton et al. 2001).
The Review Team was unable to determine whether health-promotion messages about reducing alcohol consumption among people living with hepatitis C are having an impact on clinical outcomes.

### 3.5.2 Social and behavioural factors related to the transmission of hepatitis C

#### Sharing injecting equipment

The first National Hepatitis C Strategy points out that sharing injecting equipment has caused 80 per cent of hepatitis C infections in Australia. It states that the risk of hepatitis C transmission through injecting drug use is influenced by factors such as the method of administering drugs, the pattern and frequency of drug use, trends in the drug market, the circumstances of people using the drug, and the pharmacology of the drug. It also points out that unintended consequences of the current drug law and its enforcement could compromise hepatitis C prevention efforts.

The Review received many submissions asserting that government reticence in relation to the reform of drug law and drug policy is the most significant factor affecting the transmission of hepatitis C. The Review Team considered the evidence and found that there is a large body of medical and legal literature that:

- rejects prohibition on the basis that it promotes dangerous practices such as sharing injecting equipment, which is the primary risk factor for hepatitis C transmission
- supports decriminalisation of illicit drug use
- advocates regulation of the illicit drug market.

The Review Team found no evidence confirming the value of a ‘zero tolerance’ approach to illicit drug use in the context of hepatitis C.

The Review received evidence indicating a growth in the overall population of people who inject drugs of around 7 per cent per year. One person who presented an oral submission argued for reducing the number of people who inject drugs—that is, for alternative routes of drug use—as a means of controlling the hepatitis C epidemic. In the Review Team’s opinion, the harm associated with injecting drug use should be reduced and alternatives to injecting should be encouraged.

See also Sections 3.3.4 and 3.3.5.

#### Other factors related to transmission

The Strategy notes several other factors related to hepatitis C transmission:

- transfusion of blood and blood products before 1990, accounting for 5–10 per cent of infections
non-sterile medical or dental procedures; non-sterile tattooing, body-piercing or other skin-incision procedures; needlestick injuries and accidental exposure to infected blood or blood products; other forms of blood-to-blood contact; and mother-to-child transmission during pregnancy and delivery—about a 6 per cent risk if the mother has chronic hepatitis C and detectable viraemia

♦ a history of incarceration.

The Strategy also notes the following:

♦ Because the risk of transmission through sexual contact is considered very low, hepatitis C is not defined as a STI.

♦ Sharing of toothbrushes, razors and other personal hygiene items is not recommended given the potential for exposure to blood.

♦ The risk of transmission through medical procedures in Australia is considered minimal because of the introduction of Standard Precautions for infection control.

The Review received submissions identifying an increasing trend towards skin-penetration procedures, particularly unsafe tattooing, among adolescents. This is essentially an unregulated industry, so the potential for hepatitis C transmission is high.

The Review Team found that information about the social and behavioural factors related to the hepatitis C transmission has not advanced significantly during the term of the first Strategy and that more research is needed in these areas.

3.5.3 Uptake of treatments by people living with hepatitis C

The first National Hepatitis C Strategy supports the following principles in relation to the uptake of treatments:

♦ People with hepatitis C should have equitable access to the full range of treatments.

♦ People with hepatitis C should be involved in the planning, implementation and evaluation of treatment programs.

♦ Accessible and culturally appropriate information and education about treatment options must be provided, so that people with hepatitis C can make informed choices.

♦ The development of new and improved treatments requires continuing, sustainable basic virological and clinical research.

The Review Team found that the Strategy has not achieved its objective of increasing access to the full range of treatment and care services for people with hepatitis C.

Improving treatments and widening their availability—as well as identifying the groups that are most suitable for treatment—remain central to the response to
hepatitis C infection in Australia. Despite the fact that treatment has been available for over five years and treatment efficacy is improving, the Review Team found:

♦ Only an estimated 7 per cent of notified hepatitis C cases are being treated, noting that the data on the number of people completing treatment are inadequate (Smart et al. 2003).

♦ The models of care that exist for people with hepatitis C are inadequate.

The Review found that access to treatment is constrained by

♦ stringent eligibility criteria (S100)

♦ the geographic and physical location of treatment services

♦ cultural and language barriers

♦ homelessness

♦ incarceration

♦ experiences of discrimination in health care settings.

Many people are not eligible for treatment. Some people are not choosing to be treated. Others have not responded to treatment.

There are indications that many people infected with the hepatitis C virus remain undiagnosed; being largely asymptomatic, they have not sought testing or treatment. In the Review Team’s opinion, other management strategies need to be developed for people who elect not to have treatment, so that questions of infectivity and symptomatology can be dealt with effectively.

The Review Team is concerned that the affected community is not sufficiently well informed about the facts of treatment and its growing efficacy. Whereas response rates with interferon monotherapy were around 20 per cent, sustained response rates (‘cures’) can be obtained in 42–46 per cent of genotype 1 cases and 76–82 per cent of genotype 2 and 3 cases with current optimal regimes of pegylated interferon and ribavirin. But low numbers of people are accessing treatment, despite the overall sustained response rates of about 55 per cent. The complex administration and toxicity of the treatments deter many people.

The Review Team heard evidence that Western European countries are achieving much higher treatment levels than Australia is at present.

If people are to make informed decisions about treatment options, relevant, up-to-date information, provided in suitable formats in appropriate settings, must be available. Community-based organisations such as AIVL and the Australian Hepatitis Council and service providers such as the Multicultural HIV/AIDS and Hepatitis Service in New South Wales are doing excellent work in designing and delivering relevant information to their constituents and clients. The Review Team notes, however, that the availability of resources limits the capacity of these organisations to do such work.
Pressure on them to cater to the information and education needs of their constituents is growing. To some extent, the community sector believes it is being set up to fail. The sector requires sustained funding that is guaranteed over a five-year period, rather than annual funding, which creates uncertainty and makes it difficult to recruit staff.

The Review Team also found that there is only limited involvement of the affected community in the development and implementation of treatment programs—from planning through to evaluation.

Evidence was put to the Review that very few people who inject drugs enter hepatitis C treatment programs. Competing health priorities, as well as discrimination, were cited as barriers to access. Research has been commissioned through the National Centre in HIV Social Research to explore this. Several submissions to the Review proposed ways of removing these barriers, including a ‘one stop shop’ model of service delivery for people who inject drugs.

The Review Team found that referral to treatment is sub-optimal. The benefits of treatment should be promulgated widely. People should be provided with up-to-date information about the efficacy of treatment. They should be offered treatment. Experience with other population health problems such as tuberculosis shows that when satisfactory treatment levels are achieved there is a greater chance of reducing overall infectiousness in the community (that is, a ‘cured’ person is non-infectious) (Pitman et al. 2002).

Only basic treatment services are available for people in custodial settings. Use of these services is affected by various factors, among them access to prevention and peer support programs, the availability of competent health care professionals and sympathetic custodial staff, concern about the confidentiality of health information, complex diagnostic and treatment issues, movement in and out of custodial settings, and the lack of continuity ‘across the wall’. The Review Team examined the model of care developed by the New South Wales Corrections Health Service and found that it could be transferable across jurisdictions. People with hepatitis C in custodial settings should have available to them the range of services that is available in the general community.

Access to treatment could be improved if there were better models of care—for example, better collaboration between specialist clinics and other health service providers, extending treatment services to custodial settings, and improved service delivery for rural and regional areas. Resources are needed to amplify the medical delivery system: more multi-disciplinary staff working collaboratively with affected communities makes good sense. Resources are also needed for the development of diagnostic virology.

The Review Team found that existing health services have limited capacity to carry the current treatment load, let alone the expected future load. Workforce development is critical to increasing treatment uptake. The current emphasis on a highly specialised workforce with exclusive access to people with hepatitis C does not work. Over 210 000 people are infected with hepatitis C: there has to be a more innovative approach.

See also Section 3.3.4.
3.5.4 The social, economic and personal impacts of new hepatitis C treatments

To date, there has been little research into the social, economic and personal impacts of new hepatitis C treatments.

There is evidence that up to 20 per cent of people who enter treatment are not completing the treatment. We need to know more about the side effects of treatment and how to mitigate them. Although they are short term, they are very debilitating and interfere with a person’s ability to maintain work and family life.

The Review Team found value in a proposal to produce an anthology of the impact of hepatitis C treatments on communities and individuals. Such an anthology could lead to broader recognition of hepatitis C’s impact on the community.

The Review Team draws attention to Shiell’s (1998) economic analysis of the impact of hepatitis C infection in Australia. This study should be re-commissioned, to account for any changes in the costs associated with new treatments. The Review Team also notes the work of Dusheiko et al. (2000), who conducted an economic appraisal of hepatitis C.

The Review received insufficient evidence to enable it to assess the new hepatitis C treatments’ impact on homeless people and on people’s employment prospects (current or future).

3.5.5 Discrimination, stigma, and maintenance, care and support

Many submissions to the Review told of the effects of discrimination against people with hepatitis C; the Review Team is also aware of the findings of the inquiry into hepatitis C–related discrimination in New South Wales.

The first National Hepatitis C Strategy has not achieved its objectives of preventing discrimination and reducing the stigma and isolation people affected by hepatitis C experience. Moreover, the right of people affected by hepatitis C to participate effectively in society has not been secured through the Strategy.

Some submissions suggested that the move toward ‘zero tolerance’ policies in relation to illicit drugs will probably increase the marginalisation of people who inject drugs and so lead to greater discrimination and stigma. Many submissions cited discrimination in health care settings as posing a significant barrier to access to basic primary health care and specialist treatment services. This echoes evidence provided to the New South Wales enquiry into hepatitis C–related discrimination.

The Review Team considers that the Commonwealth should require the states and territories to implement strategies to reduce discrimination, particularly in health care settings, as a requirement of funding under a second National Hepatitis C Strategy.

See also Section 3.3.4.
3.6 EDUCATION, INFORMATION AND SERVICES IN RURAL AND REGIONAL AUSTRALIA AND IN CUSTODIAL SETTINGS

The fourth term of reference requires the Review Team to ‘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’.

3.6.1 Rural and regional services

The first National Hepatitis C Strategy recognises that access to education, skills and the necessary equipment for maintaining preventive practices is often difficult in rural, regional and remote areas of Australia. It also acknowledges that the limited availability of services in these areas has an impact on the care and support of people affected by hepatitis C. To remedy this situation, the Strategy:

♦ supports the provision of hepatitis C–related education and prevention interventions for people at risk of infection and living in rural, regional and remote areas of Australia

♦ stresses the need for appropriate health care services with a continuum of care in regional, rural and remote Australia through developing and testing innovative service-delivery models.

The Review Team found few achievements for the Strategy in these areas, although it notes that assessment of the impact of hepatitis C, given the range of health issues rural and remote communities have to deal with, is very complex.

Submissions to the Review raised the following difficulties faced by people living with hepatitis C in rural and remote parts of Australia:

♦ barriers to accessing services

♦ barriers to adhering to complex diagnostic and treatment regimes

♦ limited models of care

♦ lack of confidentiality

♦ discrimination in health care settings

♦ barriers to accessing NSPs and associated harm-reduction measures

♦ lack of support services.

In addition, several submissions discussed the lack of hepatitis C treatment services in rural and regional Australia. Because of the lengthy duration of treatment, people living in rural and regional areas and undergoing treatment require the support of a network of services. This situation is exacerbated by the discrimination that often
occurs in health care settings; discrimination is often more acute in small communities than in the cities, with the relative anonymity they afford.

The Review Team found that some Commonwealth-funded program activity—for example, several satellite broadcasts on hepatitis C treatments and management and the provision of distance-based learning modules—has improved access to information, education and training for service providers in rural and regional areas. There is also some evidence that states and territories are developing policies and investing in services to improve access to treatment and care for people with hepatitis C in rural and regional areas.

The Review Team examined the question of the distribution of the health workforce and found that more information is needed about where they are located and their competencies in hepatitis C diagnostics (including pre- and post-test counselling), treatment and care. The Team considers that telemedicine initiatives would be useful in rural and regional areas.

At present many people in rural and regional areas have to travel vast distances to attend specialist clinics. New models of care are needed. One option would involve linking tertiary treatment centres with peripheral care to improve access: pre-treatment work-ups could be done locally, then one visit would be required to a specialist facility; a local clinician competent in hepatitis C could initiate and monitor treatment (similar to models of care for custodial settings).

There is also a serious shortage of ancillary health care workers in rural and regional areas.

Submissions to the Review did not provide adequate information about the implementation of infection-control guidelines—including for oral (dental) health—in rural and regional health care settings.

### 3.6.2 Custodial settings

In this context, custodial settings includes prisons, juvenile justice centres, and remand and other detention centres.

The first National Hepatitis C Strategy notes that in custodial settings there are severe limitations on access to education, the means of preventing transmission, and infection control. It asserts that being incarcerated should not be a barrier to obtaining treatment for hepatitis C and that such settings offer ample opportunity for health maintenance and treatment interventions. It further notes that, while some treatment programs have been established successfully in some custodial environments, limited access to hepatitis C treatments and lack of continuity of care for inmates are problems.

To help remedy this situation, the Strategy:

♦ encourages implementation of equitable prevention, treatment and care, and support systems in custodial settings for people with hepatitis C
supports increased access for people in custodial settings who have hepatitis C and are seeking treatment and information about treatments

promotes the expansion and availability of treatments for drug dependency in custodial settings

supports the implementation of nationally consistent standards for hepatitis C education and prevention in custodial settings

supports initiatives under the National Drug Strategic Framework that promote the diversion of people who use illicit drugs away from incarceration and into non-custodial options where the risks of hepatitis C transmission are reduced.

The Review Team found that the Strategy has not been able to effect substantial change in any of these areas.

Many more people are now moving from place to place within the corrections system. In addition, the trend towards shorter sentences means that large numbers of people enter and leave the corrections system each year. As a result of these two factors, custodial settings pose an increasingly serious ‘incubator’ risk—to inmates, to custodial staff and, upon inmates’ release, to the broader Australian community.

There is evidence that 10 per cent of people who inject drugs in prison are initiated into this practice while they are in prison. Further, people with limited literacy are over-represented in custodial settings. And, finally, the imprisonment rate for Indigenous Australians is 15 times that for the non-Indigenous population, placing this population at particular risk (Australian Institute of Health and Welfare 2001), a risk that will inevitably be transferred outside custodial settings.

The Review Team considers that custodial settings offer opportunities for intervening to educate people who are at high risk. The urgent need to provide hepatitis C education to people in custodial settings is well documented:

Prisoners are also at increased risk of contracting communicable diseases. In New South Wales, in 1996, 69% of men and 64% of women reported sharing needles in prison. One third of male and two thirds of female inmates tested positive to the hepatitis C antibody… In Australia’s prisons, prevention measures such as condoms, dental dams and clean needles are either not available or not widely available.

(Australian Institute of Health and Welfare 2001, p. 3)

Hepatitis C education and prevention activities in custodial settings are, at best, patchy. Recently published evidence documents at least seven incident cases of hepatitis C in custodial settings (Haber et al. 1999; Post et al. 2001). States such as New South Wales that once supported peer education programs in custodial settings have wavered in their commitment. Harm-reduction measures introduced in the wider community to reduce the transmission of blood-borne viruses are not uniformly available in custodial settings. Mindful of the high levels of inmates’ mobility and the short-term sentences that many inmates serve, the Review considers that peer

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5 In New South Wales about 20 per cent of all inmates inject drugs while in prison.
education is a very effective model for delivery of health-promotion measures in custodial settings. Peer educators are credible information sources.

In connection with custodial settings, the Review found inconsistent support from the states and territories for harm-reduction measures to reduce hepatitis C transmission and for the use of pharmacotherapies to treat dependency on illicit drugs. Access to hepatitis C treatments is capricious and inadequate. And inmates’ confidentiality in terms of their health and personal safety is not being protected.

The Review Team notes evidence that NSPs operate in some custodial settings in Spain, Germany and Switzerland; there are two medically supervised injecting rooms in custodial settings in Switzerland. Evaluations of these strategies could well inform harm-reduction measures in Australian custodial settings.

The Review notes that ANCAHRD’s Clinical Trials and Research Committee commissioned a paper on models of care for hepatitis C in prisons. The draft paper is now being circulated and has generated useful discussion on what constitutes an appropriate range of health services in custodial settings. It could result in a generic model of health services for people in custodial settings—a matter that is currently on the agenda of the Australian Health Ministers Advisory Council.

In the Review Team’s opinion, a second National Hepatitis C Strategy should refocus attention on achievable improvements in health care for inmates of custodial settings and their families.

See also Sections 3.3.4 and 3.3.10 and Sections 3.5.3 and 3.5.5.
3.7 SURVEILLANCE

The fifth term of reference requires the Review Team to ‘assess the appropriateness and effectiveness of hepatitis C surveillance mechanisms’.

The first National Hepatitis C Strategy states,

Improved monitoring and surveillance of the hepatitis C epidemic in Australia are necessary to provide information to support the implementation of this Strategy. Surveillance mechanisms are used to monitor the prevalence and incidence of hepatitis C in our community, to identify those at risk of infection and so enable accurate targeting of prevention and care interventions, and to provide data to assist in the evaluation of these interventions.

Improved monitoring and surveillance will also increase our knowledge of the long-term consequences of hepatitis C infection. To achieve this, the Communicable Diseases Network of Australia and New Zealand has recently endorsed the Australian Hepatitis C Surveillance Strategy, which makes provision for improved notification protocols and improved mechanisms for monitoring and surveillance of hepatitis C in Australia.

The Review Team found modest achievements for hepatitis C surveillance during the term of the Strategy. Given the nature of the unfolding epidemic, and the lessons learnt from the strength of the surveillance system developed for incident HIV cases, the Team considers that temporary activities taken up by the states and territories need augmenting. It notes, however, that surveillance is extremely difficult for the states and territories.

The National Centre in HIV Epidemiology and Clinical Research’s HIV/AIDS, Viral Hepatitis & Sexually Transmissible Infections in Australia—annual surveillance report 2001 provides the most recent published evidence about the state of the hepatitis C epidemic in Australia (National Centre in HIV Epidemiology and Clinical Research 2001). During the year 2000 there were 20,926 notifications of hepatitis C infection reported, bringing to more than 160,000 the number of cases of hepatitis C notified in Australia since antibody testing became available in 1990. The number of notifications between 1996 and 2000 remained relatively stable, in the range of 18,000 to 22,000 a year. The Review Team notes, however, the likelihood that many people with hepatitis C infection remain undiagnosed.

There may be up to 16,000 new infections each year, and there could be up to 250,000 people living with hepatitis C virus antibodies. By 2020 there could be 500,000 people in Australia living with the antibodies (Hepatitis C Virus Projections Working Group 2002).

The Review Team notes the value of the sentinel surveillance already done through the annual NSP survey but notes, too, that this surveillance is currently limited to community-based NSPs and would benefit from expansion into adult and juvenile custodial settings. It sees a need for a continuous flow of data to assist with policy and program development at the Commonwealth and state and territory levels: such data have been fragmented to date. The Review Team found that the surveillance activity carried out by the National Centre in HIV Epidemiology and Clinical Research has been crucial to the success of the Strategy.
Nevertheless, hepatitis C surveillance based on prevalence data limits the effectiveness of the surveillance in tracking the evolving epidemic. A new system is being trialled in all states and territories except Queensland to refine a proxy for an incident case; if this trial proves successful, hepatitis C surveillance will become more effective.

The efforts to identify new infections are commendable, but the momentum must be maintained if the evolution and impact of the hepatitis C epidemic are to be properly assessed. Further development of hepatitis C surveillance will require considerable expertise and resources.

The Review Team found that strategies to improve data collection on the incidence and prevalence of hepatitis C infection among Aboriginal and Torres Strait Islander peoples need to be improved.

See also Section 3.3.
3.8 THE ECONOMIC IMPACT OF HEPATITIS C

The sixth term of reference requires the Review Team to ‘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’.

The economic impact of hepatitis C infection in Australia, including the cost to the community and government expenditure on hepatitis C, has been documented to some extent (Shiell 1998). A health economic appraisal of hepatitis C treatments has also been published (Dusheiko et al. 2000). With new estimates indicating an increase in notifications—16,000 new infections a year—and up to 250,000 people living with hepatitis C antibodies, it is important to revisit this subject.

Public hospital services (delivered on site in a public hospital or as outreach services) and general practitioner services are funded through the Australian Health Care Agreements (1998 to 2003) and Medicare respectively. The Pharmaceutical Benefits Schedule and the Pathology Services Table of the Medicare Benefits Schedule offer affordable access to hepatitis C treatments and funding for the investigation of hepatitis C infection.

For many years, the Pharmaceutical Benefits Scheme, which was introduced in 1948 to give all Australians access to a free list of life-saving medicines, has worked well. But the nature of the disease burden in Australia and the technologies used to treat illness have changed over time, and the current system is not designed to carry the increased cost burden of these changes. In the last 10 years, the cost of the PBS has grown from $1 billion to over $3 billion. In the 2002 Federal Budget the Government attempted to combat this problem to some extent through a range of adjustments. Cost recovery through increasing co-payments on PBS medications is recognised as politically unacceptable, and reallocation of other Commonwealth funds to support the burgeoning PBS is not permitted. Alternative models for funding of highly specialised drug treatments are under consideration. The Review Team notes that licensing arrangements between large pharmaceutical companies and small biotechnology companies are forcing up the cost of new drug treatments.

As more people begin treatment for hepatitis C through the Highly Specialised Drugs Program funded through the PBS (S100)—with combination therapy or the soon-to-be-listed pegylated interferon—pressure on the PBS will continue to grow.

The Review Team notes two important barriers to assessing the economic impact of hepatitis C infection:

♦ lack of information-sharing between the agencies responsible for data collection

♦ limited research into the costs to the community of the impact of new treatments.

The level of resources required at the Commonwealth and state and territory levels to reduce the future public health burden of hepatitis C is potentially great and definitely underestimated. The Review Team notes, however, that expenditure on prevention of hepatitis C infection will be offset against future savings on end-stage treatment of hepatitis C–related liver disease and liver transplants.

See also Section 3.5.
3.9 LINKS WITH OTHER NATIONAL STRATEGIES

The seventh term of reference requires the Review Team to:


The first National Hepatitis C Strategy states,

Optimal implementation of the National Hepatitis C Strategy demands coordination with other national population health initiatives that have a bearing on the health and wellbeing of people affected by hepatitis C. Among these initiatives are the National HIV/AIDS Strategy, the National Mental Health Strategy, the National Health Plan for Young Australians, the National Suicide Action Plan, the National Immunisation Strategy, and the Australian Hepatitis C Surveillance Strategy.

It identifies opportunities to link with the following:

♦ the National HIV/AIDS Strategy 1999–2000 to 2003–04—particularly in terms of promoting the removal of legal impediments to preventing transmission of blood-borne viruses

♦ the National Drug Strategic Framework 1998–99 to 2002–03 and the National Action Plan on Illicit Drugs 2001 to 2002–03—for example, reducing the prevalence of risk behaviours such as injecting drug use and supporting the availability of effective and accessible treatments for drug dependency (including in custodial settings) and related diversionary initiatives

♦ the Australian Hepatitis C Surveillance Strategy, the National Indigenous Australians’ Sexual Health Strategy 1996–97 to 1998–99 (as extended), the National Mental Health Strategy and Healthy Horizons: a framework for improving the health of rural, regional and remote Australians.

3.9.1 The National HIV/AIDS Strategy

The National Hepatitis C Strategy states, ‘Inclusion of hepatitis C under the aegis of the National HIV/AIDS Strategy 1996–97 to 1998–99 strengthened the commitment to tackling the epidemic’ and:

In particular, inclusion of hepatitis C under the aegis of the third National HIV/AIDS Strategy provided State and Territory governments with the opportunity to capitalise on established programs and infrastructures that targeted common risk factors (such as injecting drug use) and broaden the scope of these initiatives to incorporate hepatitis C–related matters.

It also identifies opportunities to:

♦ support efforts under the National HIV/AIDS Strategy to develop an ‘enabling environment’ and promote the removal of legal impediments to the prevention of transmission of blood-borne viruses
link the health education and maintenance and care and support needs of people with hepatitis C in custodial settings with activities conducted by ANCAHRD under the National HIV/AIDS Strategy.

Submissions to the Review provided evidence that links with the current National HIV/AIDS Strategy have afforded hepatitis C both opportunities and threats.

Two of the most important initiatives for preventing hepatitis C—NSPs and education for people who inject drugs—were initiated and funded under successive HIV/AIDS strategies (Department of Health and Aged Care 1999). These initiatives remain central to an effective hepatitis C response, even though the epidemics are very different.

Resolution of problems of discrimination associated with HIV has some relevance for hepatitis C. The Review Team found that opportunities to deal with discrimination through links between the two Strategies have not been realised. This remains a central concern for the affected community.

The way in which successive National HIV/AIDS Strategies confronted legal impediments to a national response (decriminalisation of homosexuality) was also presented as a model for hepatitis C. The Review Team found, however, that links between the Strategies have not resulted in an ‘enabling environment’. In the absence of public policy support for harm reduction and drug law reform, legal impediments to the prevention of hepatitis C transmission remain.

The surveillance activity that skilfully shepherded the HIV response was seen as transferable, to some degree, to hepatitis C. But the Review Team found that the differences between the epidemics and the absence of a hepatitis C–defining illness limit the transferability of HIV surveillance methods. The Team nevertheless praises the surveillance work done to date and recognises that more resources are needed to develop specific competence in this area. See also Sections 3.3 and 3.7.

Before the Hepatitis C Strategy was introduced, lack of coordination between a number of strategies at the national and state and territory levels was a longstanding shortcoming (Department of Health and Aged Care 1999). An integrated response to HIV and hepatitis C—that is, two or more strategies under one broad banner—presented problems: matters specific to one disease or community could disappear from view in the bigger picture. These concerns were well founded. There is ample evidence of a lack of coordination between the current Strategies for hepatitis C and HIV/AIDS. In spite of the existence of a dedicated Strategy, hepatitis C has not received an equitable hearing.

The Review Team found that, for hepatitis C, the evolutionary process from ‘related disease’ to a degree of autonomy within the established HIV infrastructure has been supportive but conditional. The hepatitis C infrastructure has been allowed to grow on condition that it did not compete for HIV funding or an equitable power base. It remains the ‘poor cousin’.

Several submissions to the Review argued for hepatitis C’s independence from the HIV infrastructure: the coat-tails of HIV were not seen as a good place to stay.

See also Sections 3.3 and 3.4.
3.9.2 The National Indigenous Australians’ Sexual Health Strategy

The National Hepatitis C Strategy stresses that improved access to health care services for Aboriginal and Torres Strait Islander peoples is necessary. It also identifies opportunities to increase the use of the population health networks that already exist for Aboriginal and Torres Strait Islander peoples, to establish partnerships across different sectors, and to support the development of innovative responses that are culturally appropriate to the specific circumstances of Aboriginal and Torres Strait Islander peoples.

In this context, the Strategy recognises the need for links with the National Indigenous Australians’ Sexual Health Strategy 1996–97 to 1998–99 (as extended). The Review Team found little evidence of such links. Given that the nature of the epidemic among Aboriginal and Torres Strait Islander peoples is possibly different and that the future disease burden in this population is likely to be profound, this situation is unsatisfactory.

See also Sections 3.3, 3.6 and 3.12.

3.9.3 The National Drug Strategic Framework

The National Hepatitis C Strategy states,

Preventing high-risk behaviours such as injecting drug use will also be a valuable contribution to the aims of this Strategy. As a result, links and opportunities for joint efforts will be explored with the National Drug Strategic Framework 1998–99 to 2002–03, to ensure that health-promotion messages are well coordinated.

The Review Team found that neither the National Drug Strategic Framework nor the National Action Plan on Illicit Drugs pays due regard to hepatitis C. There is little evidence of effective links between the respective initiatives.

Over 90 per cent of all new hepatitis C infections occur among people who inject drugs. For this reason, the Review Team considers that health promotion strategies and messages emanating from the respective initiatives should be consistent and supportive of harm reduction.

In relation to workforce development, important opportunities lie with alcohol and other drug services and professional associations such as the Australian Professional Society on Alcohol and Other Drugs.

See also Section 3.3

3.9.4 The Australian Hepatitis C Surveillance Strategy

The Review Team notes progress with and supports the further development of the national hepatitis C surveillance system. See also Sections 3.3 and 3.7.
3.9.5 The National Mental Health Strategy

The National Hepatitis C Strategy states,

People with a mental illness and/or psychiatric disability, especially in populations with high levels of substance use, also need to be considered in the development of hepatitis C–related prevention and education interventions. Some people at risk of hepatitis C infection—such as people living in adverse social circumstances and people who are homeless or transient—are also likely to have reduced contact with mental health services and thus may not have their needs adequately assessed or met. Where appropriate, both mental health and drug services should be encouraged to participate in the development and delivery of hepatitis C–related prevention interventions.

It also identifies opportunities to:

♦ support the participation of providers of mental health services in developing and implementing hepatitis C–related education and prevention interventions

♦ establish links with the Australian Transcultural Mental Health Network, to help target people from culturally and linguistically diverse backgrounds who may be at particular risk of hepatitis C infection as a result of injecting drug use.

The Review Team found that links with the National Mental Health Strategy were virtually non-existent, and it found little evidence that the opportunities identified had been acted upon.

The Review Team notes recent research into hepatitis C’s effects on the brain and the links to depression (Foster et al. 1998; Forton et al. 2001). This research should be closely monitored, to guide mental health services for people with hepatitis C. As more people undergo hepatitis C treatment, the need for accessible counselling and mental health support will become even more critical.

3.9.6 The Healthy Horizons framework

The National Hepatitis C Strategy identifies an opportunity to support the provision of hepatitis C–related education and prevention interventions for people at risk of infection and living in rural, regional and remote areas of Australia, under the auspices of Healthy Horizons: a framework for improving the health of rural, regional and remote Australians.

Submissions to the Review provided little evidence of effective links with the framework.

There has been a proliferation of rural health schools in recent years, resulting in more research into health services’ effectiveness and organisation. More effective links need to be made with the new services that are being developed. Problems associated with discrimination and confidentiality in rural communities need to be dealt with through these new services. The Review considers that some of the funding for these new services should be earmarked for hepatitis C.

See also Sections 3.3, 3.5 and particularly 3.6.
3.10 TRANSFERABILITY OF APPROACHES

The eighth term of reference requires the Review Team to ‘examine the transferability of approaches, partnerships, principles and services in hepatitis C to other chronic diseases’.

The Review Team found that the following approaches promoted by the Strategy are transferable to the management of other chronic diseases:

♦ engaging the affected communities and other key stakeholders in the development of a response

♦ building the affected communities’ capacity to develop and implement a response

♦ identifying and breaking down barriers to access to effective services

♦ fostering a broad, multisectoral, cross-government approach to research, monitoring and evaluation, health promotion and disease prevention, and workforce development.

Hepatitis C has its own specific diagnostic, treatment and care, and lifestyle requirements. As noted in Section 3.5 innovative models of care are needed if we are to cope with current and expected demands on the health system. But this raises a question not unique to hepatitis C: how to ensure continuity of care across sectors and geographic areas?

The Review Team found that in the management of hepatitis C there is much to learn from the management of other chronic diseases. For example, like all chronic diseases, hepatitis C requires coordinated care; here, there may be lessons to be learnt from the coordinated care trials funded by the Commonwealth from 1997 to 1999.

It is the Review Team’s opinion that if an appropriate, cost-effective model of care could be developed for hepatitis C it would be transferable to other chronic diseases.
3.11 INTERNATIONAL ASSISTANCE AND COOPERATION

The ninth term of reference requires the review team to ‘examine the impact of hepatitis C in the Asia–Pacific region and the need for international assistance and cooperation in respect of hepatitis C’.

The Review Team notes that the impact of hepatitis C in the Asia–Pacific region and the need for international assistance and cooperation are not dealt with in the first National Hepatitis C Strategy. The Team did not receive sufficient information in this regard to enable it to make an adequate assessment of the situation. Neither AusAID nor ACFOA (the Australian Council for Overseas Aid) presented a submission to the review.

Hepatitis C surveillance appears to be below the Australian standard in the much of the Asia–Pacific region. It is difficult to initiate such surveillance activity in countries where life expectancy is lower and chronic disease is thus less of a problem. Notwithstanding this, the Review Team found that regional support for surveillance activities for hepatitis C forms the basis for further action.

Australia is leading the international community in responding to the hepatitis C epidemic. The National Hepatitis C Strategy 1999–2000 to 2003–04 is a pioneering document that has the potential to guide future action in countries in the Asia–Pacific region and beyond. But Australia needs to consolidate its own achievements against the aims and objectives of the Strategy: a ‘look in our own backyard’ approach needs to be fostered.
3.12 PRIORITIES, GAPS IN IMPLEMENTATION, AND BARRIERS TO SUCCESS

The tenth term of reference requires the Review Team to:

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.

Many submissions to the Review dealt with this term of reference. The key issues are summarised in the following sections; many of them are discussed in detail in other areas of this chapter.

3.12.1 New or shifting priorities

Reducing hepatitis C transmission

The Review received evidence that the number of people who inject drugs in Australia is increasing by approximately 7 per cent each year. In this context, the Review Team notes several emerging areas of need:

♦ specific peer education and prevention approaches for young women—particularly those who have been injecting for less than two years—in line with research evidence

♦ specific peer education and prevention approaches to meet the information and education needs of young users of illicit drugs

♦ specific education and information for psychostimulant users—particularly those injecting crystal and base methamphetamine

♦ culturally appropriate prevention and treatment strategies for Aboriginal and Torres Strait Islander peoples who inject drugs

♦ culturally appropriate prevention and treatment strategies for people from culturally and linguistically diverse backgrounds who inject drugs.

The Review is concerned by the growing evidence of the move away from harm reduction towards a ‘zero tolerance’ approach to illicit drug use. Law enforcement policies and practices, including random drug testing, are deterring people who inject drugs from seeking out NSPs and health care services.

The popular and political discourse is now putting greater emphasis on individual responsibility for health. This detracts from approaches based on the creation of
supportive environments for health. Further, people who inject drugs may be excluded from this discourse.

Liability insurance is emerging as a serious problem for the providers of NSPs.

**Treatment of hepatitis C infection**

Sustained response rates for treatment are now higher than when the first National Hepatitis C Strategy was developed. Despite this, treatment uptake is low. As noted in Section 3.5, people with hepatitis C are not sufficiently aware of the latest facts about treatment, its improving efficacy and the fewer side effects.

A growing body of literature is questioning the need for liver biopsy as a treatment prerequisite.

Some people are choosing to use complementary and alternative therapies to relieve the symptoms of hepatitis C infection or reduce the side effects of conventional treatment. There has been only limited research into the effectiveness of complementary and alternative therapies for hepatitis C.

Lack of access to psychiatric services in tertiary settings is emerging as a problem for people with hepatitis C, particularly those undergoing treatment.

**Health maintenance, care and support for people affected by hepatitis C**

In Section 3.6 the Review Team refers to research suggesting that hepatitis C has particular effects on the brain, with links to depression. This has implications for service delivery and should be addressed through development of protocols for people undergoing treatment.

**Preventing discrimination and reducing stigma and isolation**

Media reporting of hepatitis C continues to focus on ‘victim blaming’. This increases the stigma associated with infection and entrenches discrimination against people who are infected. A more compassionate society would focus on changing environments, rather than blaming individuals, since a changed environment can bring tangible health benefits.

### 3.12.2 Gaps in implementation

Most of the gaps in implementation are discussed in Section 3.3. However, the Review Team highlights the following:

- absence of an implementation plan and performance indicators for monitoring it
- lack of resources for implementation
- lack of strong, independent voice for hepatitis C through existing governance structures
weak links with other strategies
lack of nationally consistent testing guidelines
a limited range of models of care
inadequate research
only rudimentary surveillance
limited data on hepatitis C incidence, prevalence or risk factors in the Aboriginal and Torres Strait Islander population
out-of-date information about the economic impact of hepatitis C infection
insufficient appreciation of the special dental needs of people with hepatitis C
lack of education, prevention, treatment and support strategies of people with hepatitis C in rural, regional and remote areas
poor access to harm reduction and hepatitis C treatments in custodial settings.

The Review Team also notes that the question of immunising people with hepatitis C against hepatitis A and B is not dealt with in the current NHMRC immunisation guidelines.

In addition, a more sympathetic response to illicit drug use in the context of homelessness is needed. Homeless people are highly marginalised, and they are not among the population groups identified under the Strategy.

3.12.3 Barriers to achieving sustained control of hepatitis C in Australia

Controlling hepatitis C transmission is the first barrier. Without overcoming it, we cannot achieve sustained control. Submissions to the review cited many barriers to achieving sustained control of hepatitis C in Australia, among them the following:

current drug laws and drug policies
lack of resources for implementation
a focus on risk factors and individual behaviour change
the complexities of treatment and care
lack of non-partisan support for continued implementation and development of harm-reduction strategies such as peer education and NSPs
inadequate research
only rudimentary surveillance
lack of involvement of affected communities in many aspects of hepatitis C–related research.

As can be seen, there is some overlap here with the implementation gaps that have been identified.

### 3.12.4 Summary

Australia is now in better position to act to remove the gaps in and barriers to implementation of the National Hepatitis C Strategy to June 2004:

- There is greater community awareness of hepatitis C.
- Diagnostics have advanced.
- Treatment efficacy is improving.
- Models of care are being developed to meet identified needs.
- Research and surveillance are improving.

The Review Team notes, however, that there is no expectation of increased resources to further implement the Strategy at this time.
3.13 APPENDIX A   THE TERMS OF REFERENCE FOR THE REVIEW

On 28 March 2002 the Commonwealth Minister for Health and Ageing, Senator the Hon Kay Patterson, approved the following Terms of Reference for the review of Australia’s first 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.


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.
3.14 APPENDIX B WRITTEN SUBMISSIONS

The following organisations presented written submissions to the Review of the National Hepatitis C Strategy. Three individuals also presented submissions.

Association of Needle and Syringe Programs Inc. (Victoria)
Australasian Society for HIV Medicine
Australian Dental Association
Australian Hepatitis Council
Australian Injecting and Illicit Drug Users League
Australian Liver Association
Australian National Council on Drugs
Australian Professional Society on Alcohol and Other Drugs
Australian Red Cross Blood Service
Blood Borne Virus Consortium of Victoria
Corrections Health Care Services, ACT Community Care
Department of Health, Western Australia
Department of Human Services, South Australia
Department of Justice, Health Services Directorate, Western Australia
Department of Justice, Office of the Correctional Services Commissioner, Victoria
Haemophilia Foundation Australia
Health Insurance Commission
Hepatitis C Committee, Australian National Council on AIDS, Hepatitis C and Related Diseases
Hepatitis C Council of New South Wales
Hepatitis C Council of Queensland
Hepatitis C Council of South Australia
Hepatitis C Council of Victoria
Indigenous Australians Sexual Health Committee, Australian National Council on AIDS, Hepatitis C and Related Diseases
Infection Management Section, Communicable Diseases and Health Protection Branch, Population Health Division, Commonwealth Department of Health and Ageing

Inter-Governmental Committee on AIDS, Hepatitis C and Related Diseases

Ministerial Advisory Committee on Hepatitis, New South Wales

National Aboriginal Community Controlled Health Organisation

National Centre in HIV Epidemiology and Clinical Research

National Drug and Alcohol Research Centre

National Drug Research Institute, Curtin University, Western Australia

National Health and Medical Research Council

National Serology Reference Laboratory

New South Wales Department of Health

Office for Aboriginal and Torres Strait Islander Health, Commonwealth Department of Health and Ageing

Pharmacy Guild of Australia

Public Health Laboratory Network

Queensland Government, Department of Corrective Services

Queensland Health, Communicable Disease Unit

Queensland Health, Rockhampton Liver Clinic

Royal College of Pathologists of Australasia

Special Access and Coordination Section, Pharmaceutical Access and Quality Branch, Health Access and Financing Division, Commonwealth Department of Health and Ageing

Tasmanian Council on AIDS, Hepatitis and Related Diseases

Therapeutic Goods Administration

Turning Point Alcohol and Drug Centre, Victoria
3.15 APPENDIX C  ORAL PRESENTATIONS

The Review of the National Hepatitis C Strategy heard 10 oral presentations:

♦ Association of Needle and Syringe Programs Inc.—Mr John Ryan, Executive Officer

♦ Australasian Society for HIV Medicine—Ms Levinia Crooks, Executive Officer, and Dr Greg Dore

♦ Australian Hepatitis Council—Mr Jack Wallace, Executive Officer

♦ Australian Injecting and Illicit Drug Users League—Ms Annie Madden, Executive Officer, and Ms Tamara Speed, President

♦ Hepatitis C Committee, Australian National Council on AIDS, Hepatitis C and Related Diseases—Professor Robert Batey, Chair

♦ Australian National Council on Drugs—Major Brian Watters (Salvation Army), Chair, and Mr Gino Vumbaca, Executive Officer

♦ Hepatitis C Council of NSW—Mr Stuart Loveday, Executive Officer

♦ Indigenous Australians Sexual Health Committee, Australian National Council on AIDS, Hepatitis C and Related Diseases—Associate Professor Cindy Shannon, Chair

♦ Ministerial Advisory Committee on Hepatitis, New South Wales—Dr Alex Wodak and Mr Stuart Loveday

The Chair of the Review Team also interviewed Professor Dick Smallwood, Chief Medical Officer, Commonwealth Department of Health and Ageing, and Professor John Kaldor from the National Centre in HIV Epidemiology and Clinical Research.
3.16 APPENDIX D  HEPATITIS C IN AUSTRALIA: BACKGROUND

As Australia’s most commonly diagnosed notifiable disease, hepatitis C poses a serious threat to population health. It is transmitted through blood-to-blood contact—as can occur, for example, through sharing drug-injecting equipment. A specific laboratory test for hepatitis C has been available only since early 1990. There are at least nine different genotypes, or strains, of hepatitis C. Previous infection with one strain of the virus does not protect against re-infection with the same or a different strain. The seroconversion ‘window period’ ranges from 54 to 192 days, during which time antibodies cannot be detected. Nucleic acid testing, a new technology introduced in Australia from June 2000, can detect the virus directly; it effectively reduces the window period to 23 days, on average.

At present there is no vaccine to protect against hepatitis C.

A review of the natural history of hepatitis C found that if 100 people are infected with the virus the outcome will be as follows:

♦ About 15 to 35 people will clear the virus spontaneously within two to six months of infection and will neither develop a chronic infection nor risk developing advanced liver disease. These people can, however, be re-infected with hepatitis C if they are re-exposed.

♦ About 65 to 85 people will develop chronic hepatitis C infection.

♦ About five to 10 people with chronic hepatitis C infection will have progressed to cirrhosis after 20 years of infection (rising to 20 people after 40 years of infection). Among the factors associated with an increased risk of cirrhosis are alcohol consumption, HIV or hepatitis B co-infection, older age at the time of infection, and being male.

♦ About three to five people with hepatitis C–related cirrhosis will be at risk of liver failure or hepatocellular carcinoma after 30 to 40 years of infection. Among people with cirrhosis, the risk of liver cancer is 1 to 3 per cent a year.

♦ The majority of people with chronic hepatitis C infection will probably not progress to advanced liver disease but their quality of life may be diminished.

In 2002 the Hepatitis C Virus Projections Working Group of the ANCAHRD Hepatitis C Committee estimated that around 210 000 people were living with hepatitis C antibodies, that there were approximately 16 000 new infections in 2001, and that up to 250 000 people were living with hepatitis C antibodies. By 2020 there may be 500 000 people in Australia living with hepatitis C antibodies.

Over 90 per cent of new infections occur in the context of injecting drug use.
3.17 BIBLIOGRAPHY


Batey R 2002, ‘Hepatitis C: where are we at and where are we going?’ *Medical Journal of Australia*, vol. 176, 15 April.


Department of Health and Ageing 2002b, *Return on Investment in Needle and Syringe Programs in Australia*, Report prepared by Health Outcomes International in association with the National Centre in HIV Epidemiology and Clinical Research and Professor Michael Drummond, DoHA, Canberra.


Smart J, Jones T, Batey R, Murphy, G 2003, ‘Hepatitis C- Why have so few patients been Treated?’, *International J Gastro* In Press


Review of the National Hepatitis C Strategy
REPORT OF THE 2002 REVIEW OF STRATEGIC RESEARCH AND THE NATIONAL CENTRES IN HIV RESEARCH

July 2002
2002 REVIEW OF STRATEGIC HIV/AIDS, HEPATITIS C AND INDIGENOUS SEXUAL HEALTH RESEARCH AND THE NATIONAL AND COLLABORATING CENTRES IN HIV RESEARCH

Dr Linda Selvey
Associate Professor Ian Anderson
Professor John Mathews
Professor Sally Redman
Dr Stuart Shapiro
4.1 SUMMARY AND RECOMMENDATIONS

4.1.1 Summary

This report examines the central elements of Australia’s research efforts in the areas of HIV/AIDS, hepatitis C and the sexual health of Indigenous Australians. It is part of the broader review of Australia’s public health response in these areas, which also includes reviews of the fourth National HIV/AIDS Strategy and the first National Hepatitis C Strategy.

The report contributes to the overall review by drawing together the principal findings of the quinquennial reviews of the National Centres in HIV Research, examining the historical context and contemporary requirements for research and recommending directions for future action.

Although some of the report’s recommendations call for changes to existing arrangements, this should be considered against the background of Australia’s world-class record of achievement in HIV/AIDS research. In terms of quality and the capacity of research to inform policy and practice, many aspects of Australian research in HIV/AIDS continue to be at the forefront internationally. The components of the research effort—principally the National Centres in HIV Research and their collaborating centres and partners—have consolidated their positions as core assets in Australia’s public health response to HIV/AIDS. They have done this not only by conducting high-quality research but also by engaging the affected communities in setting research priorities and research dissemination, actively working to put research results into practice, and participating in policy development. These aspects of the National Centres’ work need to be preserved. Cures and vaccines for HIV/AIDS, hepatitis C and STIs continue to elude us, but continued investment in a dedicated research program is essential to effective prevention, education, treatment and care.

The changing nature of the HIV/AIDS and hepatitis C epidemics and changing patterns of STIs, along with the evolution of health sector research funding and management do, however, present considerable challenges to future research efforts in these areas.

In particular, there is now a need to clarify the distinction between the various types of research and the most suitable support structures for each type. One facet of this concerns the positioning of investigator-initiated basic research within competitive grant programs (such as those administered by the NHMRC) and the positioning of core-funded research to optimise the development of health policy and programs. In addition, there is a pressing need to consider the position of hepatitis C research—in particular, funding levels and the involvement of research funding bodies such as the NHMRC. Similarly, it is also timely to consider the best way of funding and structuring research into Indigenous Australians’ sexual health.

As Australian research in this area has evolved, so have the needs of the communities, individuals and organisations who rely on that research to provide an intellectual and informational base for their work. New ways of developing, communicating and assessing research priorities should now be forged. This report examines how all interested parties might be better served by improved processes for priority setting. The processes should seek to secure the best health outcomes whilst at the same time respecting the roles and responsibilities of all who have an interest in this research.
Having regard to the challenges of the HIV and hepatitis C epidemics, both in Australia and regionally, this report also highlights the importance of developing new ways of engaging with governments and with organisations responsible for HIV and hepatitis C policy and programs; this includes the states and territories and governments in the Asia–Pacific region.

As well as suggesting new ways of creating links into and out of research, the report offers a number of recommendations for maximising the relative strengths of the various components of the research response to the epidemics. It calls for funding bodies and host institutions to carefully consider the value of the assets represented by the National Centres in HIV Research and to structure future funding and support in such a way as to increase the value of those assets. This may involve further expanding the involvement of funding bodies such as the NHMRC and the Australian Research Council. It will, however, be necessary to retain the most successful and valuable features of Australia’s highly regarded HIV/AIDS, hepatitis C and Indigenous sexual health research efforts, in order to ensure the research’s continuing relevance and effectiveness.

### 4.1.2 Recommendations

The Strategy Research Review Team recommends as follows:

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<tr>
<th>Recommendation</th>
<th>Details</th>
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<tr>
<td>89.</td>
<td>That the outgoing Director of the National Centre in HIV Virology Research be congratulated for the Centre’s excellent work in carrying out important, internationally recognised research that is of very high quality and significance.</td>
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<tr>
<td>90.</td>
<td>That the National Centre in HIV Virology Research, under the leadership of a Director, develop a strategic plan for the duration of its current funding cycle. This plan should guide the Centre’s progress towards obtaining competitive funding; it should also include the important core research work (research that is highly strategic but may not necessarily be innovative). The strategic planning process should involve all stakeholders, including the HIV/AIDS advisory structure and the Department of Health and Ageing.</td>
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<td>91.</td>
<td>That scientists in the National Centre in HIV Virology Research review areas of commonality between the hepatitis C and human immunodeficiency viruses and their immunovirology and strengthen links with virologists working on hepatitis C in Australia and elsewhere. Where appropriate, funding could be sought for this research through the competitive grant processes.</td>
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<tr>
<td>92.</td>
<td>That the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society be congratulated for their high-quality, internationally recognised work in HIV social research.</td>
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<td>That—where it is possible, feasible and appropriate—the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society engage with National Centres on Drug Research when doing work relating to injecting drug users.</td>
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<td>94.</td>
<td>That the Director and Deputy Director of the National Centre in HIV Epidemiology and Clinical Research be congratulated for their outstanding achievements in HIV epidemiology, surveillance and clinical research.</td>
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95. That block funding for the National Centre in HIV Virology Research cease at the end of December 2004.

96. That a process be developed and funds be identified for purchasing ‘core research’ in HIV virology and immunovirology.

97. That a process be developed and funds be identified for purchasing a networking and communication function for research in HIV virology and immunovirology and that this function be placed with one of the laboratories or institutions that has received funding for the core research.

98. That there be no restrictions on National Centre in HIV Virology Research researchers applying for NHMRC or Australian Research Council funding as a result of receiving funding for core research or the networking function.

99. That the researchers currently involved in the National Centre in HIV Virology Research be encouraged to apply jointly for funding for the ‘core research’ and networking function.

100. That the researchers currently involved in the National Centre in HIV Virology Research be supported and encouraged to develop expertise in obtaining competitive funding to pursue innovative investigator-initiated research.

101. That the Population Health Division of the Department of Health and Ageing continue to fund the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society for at least the next five years—initially, through a new five-year funding agreement.

102. That a new process for determining the research priorities of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society, drawing in other researchers and stakeholders, be developed.

103. That both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society be encouraged to nurture social research outside Sydney and Melbourne through collaborative projects and mentoring. This would include developing HIV social research expertise outside the two major Centres.

104. That both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society—and the former in particular—pursue their host universities for increased support, in recognition of the kudos they bring to their hosts.

105. That the processes of funding and administering the funding of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society remain with the Population Health Division of the Department of Health and Ageing. Should the Department choose to transfer this function to another body, however, the conditions specified in recommendations 101 to 104, and any others that may be identified by the advisory structure in consultation with the two Centres, should still be met.
106. That the Population Health Division of the Department of Health and Ageing continue to fund the National Centre in HIV Epidemiology and Clinical Research for at least the next five years—initially, through a new five-year funding agreement.

107. That the National Centre in HIV Epidemiology and Clinical Research pursue its host university for increased support, in recognition of the kudos it brings to its host.

108. That the National Centre in HIV Epidemiology and Clinical Research explore ways of expanding the reach of its expertise—particularly in communicable diseases surveillance and in conducting clinical trials in the primary care setting—into other areas of concern to the Population Health Division.

109. That the Population Health Division continue to provide the National Centre in HIV Epidemiology and Clinical Research with additional funds for hepatitis C surveillance and that these funds be rolled into the Centre’s core funding.

110. That the processes of funding and administering the funding of the National Centre in HIV Epidemiology and Clinical Research remain with the Population Health Division. Should the Department choose to transfer this function to another body, however, the conditions specified in recommendations 106 to 109, and any others that may be identified by the advisory structure in consultation with the Centre, should still be met.

111. That strategic hepatitis C research be acknowledged as central to the Australian response to hepatitis C. Processes should be set up and resources allocated accordingly.

112. That the Population Health Division explore with the NHMRC and the Australian Research Council ways of funding a program of hepatitis C research over a long-term time frame, such as through Partnership funding.

113. That the Department of Health and Ageing explore ways in which research into the sexual health of Indigenous Australians, as well as hepatitis C and HIV in this population, can be supported and funded through appropriate mechanisms, integrating this with the current reform agenda in Aboriginal research that is being developed nationally.

114. That the Population Health Division resume dialogue with AusAID with a view to obtaining funding support for Australian researchers to work in HIV-related research in the Asia–Pacific region.

115. That the Population Health Division explore ways of accessing research expertise to assist with the management of a research program, including developing priorities for research and translating the research results into policy and practice.

116. That the Clinical Trials and Research Committee of ANCAHRD be abolished and a revised advisory structure be formed, with HIV/AIDS, hepatitis C and Indigenous sexual health committees having a mixture of policy and research expertise. The advisory structure’s overarching body should have only minimal influence on the work of these committees.
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<td>117.</td>
<td>That there be a triennial time frame for setting research priorities in the areas of HIV/AIDS, hepatitis C and the sexual health of Indigenous Australians. All the relevant stakeholders should be involved in deciding the priorities, and the process should include a review of research undertaken to that time.</td>
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<td>118.</td>
<td>That the research priorities determined for each three-year period be communicated to the NHMRC and the Australian Research Council, with a view to influencing funding decisions. The priorities should be used to assess the significance of competitive grant applications in the areas of HIV/AIDS, hepatitis C and Indigenous Australians’ sexual health.</td>
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<td>119.</td>
<td>That, wherever possible, competitive funding sources be used for funding priority research and that core funding provided to the Centres be used for research that is of the highest priority and/or would be unlikely to be funded through competitive processes.</td>
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<td>120.</td>
<td>That the NHMRC, the advisory structure replacing the Clinical Trials and Research Committee, and the Population Health Division of the Department review the practice of restricting competitive grant applications by the Centres, with a view to removing the restrictions in the light of the processes recommended here.</td>
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<td>121.</td>
<td>That the role of the Centres’ Scientific Advisory Committees be strengthened and broadened to include overseeing, monitoring and communication tasks. The name ‘Scientific Advisory Committee’ might need to be changed to reflect this.</td>
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4.2 THE REVIEW PROCESS

In order to support the 2002 reviews of the National HIV/AIDS Strategy 1999–2000 to 2003–04 and the National Hepatitis C Strategy 1999–2000 to 2003–04, a separate process for reviewing the status and future of Australia’s research efforts in HIV/AIDS, hepatitis C and related diseases was established. The purpose of the Strategy Research Review was:

♦ having regard to the outcomes of the 2002 quinquennial review of the National Centres in HIV Research and submissions from key stakeholders, to assess the effectiveness of the current national research centre approach to supporting the objectives of the National HIV/AIDS Strategy, the National Hepatitis C Strategy and the Indigenous Australians’ Sexual Health Strategy

♦ to develop recommendations on the most appropriate method or structure for supporting such research into the future.

Section 4.10 (Appendix A) shows the full Terms of Reference.

The members of the Strategy Research Review Team were:

♦ Dr Linda Selvey, Manager Communicable Diseases Unit, Queensland Health (Chair)

♦ Associate Professor Ian Anderson, Koori Health Research and Community Development Unit and Centre for the Study of Health and Society, University of Melbourne

♦ Professor John Mathews, Medical Director, Population Health Division, and Deputy Chief Medical Officer, Commonwealth Department of Health and Ageing

♦ Professor Sally Redman, NHMRC

♦ Dr Stuart Shapiro, Division of AIDS, US National Institutes of Health.

Secretariat support was provided by Paul Lehmann (Director) and Debra Gradie (Assistant Director), HIV/AIDS Section, Commonwealth Department of Health and Ageing.

Interested parties were invited to make submissions to the review. Sixteen submissions were received and considered by the Review Team. Written submissions specific to the Review Team’s Terms of Reference were received from:

♦ the Australian Federation of AIDS Organisations

♦ the Australasian Society for HIV Medicine

♦ the Blood Borne Virus Consortium of Victoria

♦ the Victorian Department of Education, Employment and Training

♦ the Indigenous Australians’ Sexual Health Committee of ANCAHRD

♦ the Office for Aboriginal and Torres Strait Islander Health, Commonwealth Department of Health and Ageing.
The Review Team also considered submissions presented to the various panels responsible for the quinquennial review of the National Centres in HIV Research.

The Review Team convened in Sydney from Monday 3 June to Friday 7 June 2002. It interviewed a range of stakeholders and other interested parties between 3 and 5 June. Section 4.11 (Appendix B) shows the program of interviews and details of the parties who attended.
4.3 BACKGROUND

[Dedicated funding for HIV/AIDS research in Australia was introduced in the mid-1980s, although Australian researchers had been working on AIDS for some time before this, particularly in Sydney, where the epidemic first appeared. Initially, the Commonwealth’s response to supporting such research was developed within the NHMRC framework: the NHMRC established the Working Party on AIDS in 1983; and in 1985 the AIDS Task Force used the NHMRC procedures to assess and support a number of applications for AIDS research, notably two cohort studies—the Social Aspects for the Prevention of AIDS Study and the Sydney AIDS Study Group. In 1986 two research centres were established, drawing together a number of existing project grants. The centres focused on virology research (the National Centre in HIV Virology Research, based at Fairfield Hospital in Melbourne) and epidemiology and clinical research (the National Centre in HIV Epidemiology and Clinical Research, based in Sydney).

In 1987 the research program was separated from the NHMRC upon establishment of the Commonwealth AIDS Research Grants Committee (CARG), which reported to the Australian National Council on AIDS. The CARG Committee initially modelled its processes on those of the NHMRC, including the design of grant application forms and the preparation of a ‘case for funds’, a mechanism replaced after 1989 by the funding of research through the framework of the National HIV/AIDS Strategies. During the 1989–1993 term of the first National HIV/AIDS Strategy significant increases in research funding were forthcoming.

The CARG Committee’s immediate challenge was to develop ways of overseeing a research program that needed to be closely linked to the National HIV/AIDS Strategy. There were four main components to this challenge:

♦ developing priorities for research
♦ developing mechanisms for fostering research in strategic areas
♦ linking research with practice
♦ reflecting the partnership approach of the National HIV/AIDS Strategy in the research program.

Over time the Committee also modified the application forms and assessment procedures in an effort to accommodate the necessary diversity of research methods. Although initially the Committee had only one medical social scientist as a member, this later changed with the inclusion of researchers reflecting a broader range of disciplines.

The first National HIV/AIDS Strategy also saw the establishment of a third research centre, the National Centre in HIV Social Research, in 1990, as a network. The Centre was located at the University of Queensland, with two Sydney nodes involving social researchers who had also previously been active in this area.

The CARG Committee established three study groups to assess proposals for research: virology and immunology; clinical research and epidemiology; and social and behavioural]
research. These groups examined applications and independent peer assessors’ reports of those applications, and their recommendations were combined to make overall funding recommendations through the Australian National Council on AIDS to the Minister for Health.

The research program was evaluated in 1992 as part of a review of the first National HIV/AIDS Strategy. The evaluation report noted, ‘Australian HIV/AIDS researchers have made significant contributions to the understanding of HIV/AIDS, both in Australia and internationally’ and went on to recommend improved coordination and management of the three Centres and simplification of the objectives of the research program. It also foreshadowed a gradual transfer of responsibility for research management to the NHMRC. The recommendations were incorporated in the second National HIV/AIDS Strategy 1993–94 to 1995–96.

The second National HIV/AIDS Strategy built on emerging knowledge from both the national and the international perspectives, observing that the epidemic appeared to have stabilised and remained largely concentrated in particular population groups, most notably homosexually active men. In the Strategy the first indications were given of ‘mainstreaming’—working to integrate HIV/AIDS approaches into more generic programs and services, particularly for communicable diseases and research.

In 1993 responsibility for the CARG Committee secretariat was transferred from the Department of Health to the NHMRC, and in 1994 the three HIV Research Centres moved to five-year funding with reviews scheduled in the fourth year, in keeping with procedures for block funding by the NHMRC. In 1995 responsibility for managing CARG project grants was also transferred to the NHMRC, which initially recorded CARG grant applications separately but in later years included them with other applications for NHMRC Project Grants. In 1996 the CARG Committee was reconstituted as the Research Advisory Committee of what was by now called the Australian National Council on AIDS and Related Diseases (ANCARD). While the NHMRC did the processing and ranking of applications and managed funded projects, the CARG secretariat returned to the Department of Health. Recommendations for funding were still made by ANCARD via the NHMRC to the Minister for Health, on the basis of the rankings provided by the NHMRC.

The HIV/AIDS research program was re-evaluated as part of the evaluation of the second National HIV/AIDS Strategy in 1995, which was undertaken by Professor Richard Feachem of the London School of Hygiene and Tropical Medicine. The evaluation drew on the outcomes of Australian research in the field and on a series of specifically commissioned studies in the areas of epidemiology, economic evaluation, and analysis over time of social and behavioural aspects among groups experiencing elevated levels of vulnerability to infection.

Professor Feachem’s report, *Valuing the past ... investing in the future: evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96*, noted the many contributions made by the Australian HIV/AIDS research effort and the general satisfaction with the mechanisms then used for managing the research program. The report gave more detailed consideration to the question of the relationship between research and practice, noting that responsibilities for this were not clearly delineated. In addition, some concern about the national scope of the work of the Research Centres was expressed, particularly in relation to the epidemic as experienced outside south-eastern Australia. The report also cautioned against the wholesale mainstreaming of HIV/AIDS research into the NHMRC, on the grounds that dedicated
HIV/AIDS research funding was still warranted and that there were concerns about maintaining links between research and policy and a capacity to respond to urgent problems. It did, however, recommend that the research program be widened to encompass communicable diseases and that

From a public health perspective, there is also the question of the declining marginal benefits of researching HIV/AIDS. There is a continuing need to maintain a research effort that monitors the pattern of the epidemic in both epidemiological and social and behavioural terms, but there may be limits to which additional research can enhance the development of public health interventions.


The prime focus for minimising HIV transmission is gay and homosexualy active men and Aboriginal and Torres Strait Islander people, but the Strategy is designed in such a way as to optimise the capacity to respond flexibly to any changes in the nature of the epidemic. Injecting drug users will continue to be identified as a high priority for education and prevention programs to control hepatitis C and to limit the possibilities of a future HIV epidemic among them.

The concept of research under the third Strategy was defined to encompass

… aspects of sexual health and communicable diseases that have an obvious and direct relationship to HIV/AIDS, which should be dealt with in a complementary and, where appropriate, integrated way in terms of policy frameworks, funding arrangements and service delivery structures, while maintaining the partnership approach.

The third Strategy further stated,

There is some overlap between HIV/AIDS and hepatitis C and other sexually transmitted diseases—in modes of transmission, affected populations, and similarities in community education approaches—and there is benefit to be gained from concurrent research. Links with existing research networks in the area of illicit drug use will be strengthened. Particular attention will be paid to ensure that this Strategy establishes strong links with the initiatives arising from the National Drug Strategy determinations. Although HIV/AIDS remains central to this Strategy, other important aspects of public health that are directly related to HIV/AIDS will be brought within the ambit of research activities.

Following the launch of the third Strategy, a new committee, the Research Advisory Committee of ANCARD, replaced the CARG Committee. The Research Advisory Committee was charged with a role that was intended to give greater emphasis to strategic considerations rather than grant management.

While supporting the continuation of dedicated funding for HIV/AIDS research, the third National HIV/AIDS Strategy clearly indicated that this was not envisaged as an ongoing arrangement: ‘It should be noted … that in the current environment of increased funding for health research the Commonwealth Government is disposed to progressively remove this type of funding arrangement, within a fixed time frame’.

In practice, the broadening of the research agenda beyond HIV/AIDS proved difficult to reflect in operational terms. The research program continued to focus almost exclusively on HIV/AIDS and only limited emphasis was given to hepatitis C–related research. The latter
was, however, the subject of a separate one-off allocation of funds, with $1 million from the NHMRC’s Strategic Research Development Committee’s Social and Behavioural Research Program into Hepatitis C being allocated in the Committee’s own budget in 1998.

The third National HIV/AIDS Strategy also anticipated that the broadening of the research program would extend the work of the Research Centres:

> These Centres have been responsible for providing information and data relevant to policy objectives. In keeping with current policy, the Centres’ research activities will include other communicable diseases, such as hepatitis C, where there is a clear and direct link to HIV/AIDS.

This was referred to in the 1997 review of the Centres, which noted and endorsed some expansion in the Centres’ activity, particularly in relation to hepatitis C research.

The 1997 review of the National Centre in HIV Social Research recommended further changes to the management of the Centre. It was recommended, among other things, that the Centre

♦ be reconstituted as a single centre under one director, with the (then) Centre for the Study of Sexually Transmitted Diseases based at La Trobe University joined as a formal collaborating centre

♦ move from Macquarie University to the University of New South Wales.

Both recommendations were subsequently put into effect.

The National Centre in HIV Epidemiology and Clinical Research and the National Centre in HIV Virology Research were also reviewed in 1997, by panels whose membership included distinguished international researchers. As part of their review, the panels were asked to advise on the value of supporting the Centres, as opposed to grants or other mechanisms. While recommending various levels of change, the review panels emphasised—in some cases very strongly—the importance of maintaining the National Centres in HIV Research as a central element of the HIV/AIDS research program. Following the 1997 review, new five-year funding agreements were entered into with each of the Centres; these funding agreements conclude at the end of December 2003. A reconstituted Scientific Advisory Committee was also established for each Centre at this time.

In responding to the review panels’ recommendations and subsequent advice from ANCARD, the Minister for Health and Family Services was, with one exception, in agreement with ANCARD’s advice. The exception related to the National Centre in HIV Virology Research review panel’s recommendation that existing funding arrangements for the Centre be maintained. The Minister preferred the view expressed in the Feachem report—that the Centre appeared to be well placed to be transferred to the NHMRC as part of the general move to mainstream research funding for HIV/AIDS.

In June 1998 the Minister requested that ANCARD and the NHMRC jointly review the current arrangements and develop a strategy to progress mainstreaming of research into HIV/AIDS and related diseases where this had been identified as the most appropriate course of action.

As a result, the joint ANCARD–NHMRC Working Party on HIV/AIDS Research Funding was formed and prepared a draft memorandum of understanding (MoU) in 1999. However,
delays associated with the establishment of both the new NHMRC and the new ANCAHRD meant that the MoU was not finalised until 2001, eventually being signed on 27 September.

The MoU details the administrative and financial responsibilities of the signatories until 31 December 2003. Importantly, it describes the arrangements whereby access to competitive funds is granted to researchers from within the Research Centres. It also establishes arrangements and time frames for the transfer of responsibility and funding for other elements of the research program, as applicable, in preparation for 2004 and beyond.

In accordance with this direction, and independently of other developments, responsibility for funding and administration of individual CARG project grants and training awards was transferred to the NHMRC from the beginning of 2001. In relation to the National Centre in HIV Virology Research, the delay in finalising the September 2001 MoU and the need to give sufficient notice to the Centre’s researchers to apply for NHMRC funding have resulted in limited progress toward mainstreaming that Centre.

The third National HIV/AIDS Strategy was reviewed in 1999 and the fourth National HIV/AIDS Strategy 1999–2000 to 2003–04, called Changes and Challenges, was released in 2000, alongside the first National Hepatitis C Strategy 1999–2000 to 2003–04. To advise the Commonwealth on implementation of these two Strategies, as well as the National Indigenous Australians’ Sexual Health Strategy, a new ministerial advisory council, ANCAHRD, was established in late 1999.

The fourth National HIV/AIDS Strategy sets out the challenges, objectives and guiding principles for HIV/AIDS research. Although mainstreaming is not specifically discussed in the Strategy document, there is reference to the need to ‘adapt successfully to the changes taking place in health and medical research as a result of the Health and Medical Research Strategic Review [the Wills review]’. The document also highlights the need for HIV/AIDS research priority setting to be informed by continuing review. Further—and for the first time in an Australian HIV/AIDS strategy—the development of vaccines for HIV is highlighted as an important area for research.

The first National Hepatitis C Strategy also highlights the importance of research in responding to the hepatitis C epidemic in Australia. The need to boost hepatitis C surveillance and monitoring efforts is noted in the Strategy document as a particular priority.

In relation to the research program, ANCAHRD’s committee structure incorporated a new committee responsible for providing advice on research matters, the Clinical Trials and Research Committee. This committee assumed responsibility for functions that were previously the province of the former ANCARD’s Research Advisory Committee and Clinical Trials and Treatments Advisory Committee. One of the Clinical Trials and Research Committee’s principle roles has been to provide advice on the content of Research Centres’ work plans, to ANCAHRD and ultimately to the Department of Health and Ageing.

The decision by the Minister for Health and Ageing in early 2002 to review the fourth National HIV/AIDS Strategy and the first National Hepatitis C Strategy, together with the scheduled quinquennial review of the National Centres in HIV Research, affords an excellent opportunity to take stock of Australia’s research efforts in these areas. The purpose of this present review is to do this and to make recommendations for the way forward, having regard to historic developments, current arrangements, and what is needed for Australia’s future response to HIV/AIDS, hepatitis C and related diseases and the sexual health of Indigenous Australians.
4.4 SCIENTIFIC QUALITY AND COMPETITIVENESS

4.4.1 The National Centre in HIV Virology Research

HIV research

The panel that reviewed the National Centre in HIV Virology Research found that the Centre is continuing to carry out internationally competitive research of the highest quality. The panel’s report is provided as Chapter 5 of this document.

The panel noted that, in spite of the limitations imposed by geographical distance, there had been significant networking and communication between the different Centre sites, and this was an important factor in improving the quality of the science. The panel considered that the Centre’s structure fosters this networking, which is difficult to foster in other circumstances.

The process of expanding the funding sources for research done by the Centre began five years ago in response to the recommendations of the 1997 quinquennial review. This process, combined with a series of difficulties culminating in the recent resignation of the Centre’s Director, has caused some disruption to the work of the Centre. This is worth noting, particularly given that the Centre has continued to produce high-quality research.

The research done by the Centre has contributed to the understanding of the replication, pathogenesis and transmission of HIV, with a view to the development of vaccines and new treatment strategies. By this definition, the research has been strategic in nature, even though it has predominantly been investigator-initiated. There has been a tension between the desire and the need to do this innovative, creative work and the need for work that is less innovative and creative but that meets a strategic need. Examples of the latter are subtyping of viral isolates and drug-resistance studies of isolates from seroconverters. Such work is referred to here as core research (monitoring and strategic research). It is essential to understanding the epidemic in Australia and to developing vaccines and treatment strategies, but it is unlikely that it would be funded through the competitive funding streams. The review panel considered this work is best done by research laboratories of high standing, rather than service laboratories, to enable the recognition of, and rapid and innovative responses to, findings that are of particular interest. However, the Centre has not always done this work, despite being urged to do so by ANCAHRD.

The panel acknowledged that the emergence of such a tension is quite natural. Innovation is by its nature more interesting and satisfying, and innovative work is important for developing a competitive track record. In addition, it seems that there have been communication failures, to the extent that participating laboratories were not always made aware of the importance of doing this kind of research. It was agreed that this work should be a fundamental component of any future work of the Centre, in its current or a different incarnation. This may necessitate the involvement of expertise not available in the Centre at present—for example, expertise in immunovirology.

All HIV research, but especially HIV virology and immunology research, is best interpreted in the context of the body of knowledge in that area. This is essential if the work is to guide Australia’s response to the epidemic. The review panel considered that the Centre’s work in interpreting HIV virology and immunology research and influencing policy and strategic
directions has to date been insufficient and should be strengthened. This is discussed in more detail in Chapter 5 of this document.

For understandable reasons, the affected communities were in the past less involved in setting priorities in HIV virology and immunology research than in other areas of the HIV research response. More recently, however, their involvement has increased, as a result of the National Association of People Living with HIV/AIDS being represented on the Scientific Advisory Committee. Improving the capacity to interpret and contextualise the research will increase affected communities’ involvement.

The review panel was satisfied that all the recommendations of the 1997 quinquennial review of the National Centre in HIV Virology Research have been met.

### Recommendation 89

That the outgoing Director of the National Centre in HIV Virology Research be congratulated for the Centre’s excellent work in carrying out important, internationally recognised research that is of very high quality and significance.

### Recommendation 90

That the National Centre in HIV Virology Research, under the leadership of a Director, develop a strategic plan for the duration of its current funding cycle. This plan should guide the Centre’s progress towards obtaining competitive funding; it should also include the important core research work (research that is highly strategic but may not necessarily be innovative). The strategic planning process should involve all stakeholders, including the HIV/AIDS advisory structure and the Department of Health and Ageing.

### Hepatitis C research

To date, the National Centre in HIV Virology Research has not been involved in significant hepatitis C research. After the 1997 review, there was an attempt to include a team working on hepatitis C virology in the Centre, but this was not agreed to by the NHMRC, which was funding the team. The human immunodeficiency and hepatitis C viruses have in common the ability to evade the host’s immune response and to form a number of different quasi-species in a single host. Areas of synergy provide opportunities for HIV virologists to expand their work and expertise into hepatitis C research. It is unrealistic, though, for this to be attempted in areas where the overlap does not exist.

### Recommendation 91

That scientists in the National Centre in HIV Virology Research review areas of commonality between the hepatitis C and human immunodeficiency viruses and their immunovirology and strengthen links with virologists working on hepatitis C in Australia and elsewhere. Where appropriate, funding could be sought for this research through the competitive grant processes.
4.4.2 The National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society

HIV/AIDS research

The panel that reviewed the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society found the work of the two Centres to be of consistently high quality and of international standing. The panel’s report is provided as Chapter 6 of this document.

The panel noted that the Centres’ research was highly relevant to and important for influencing the prevention and management of HIV infection in Australia. It found no areas of work done by the Centres using core funding that were not directly relevant to priorities set in the current National HIV/AIDS Strategy. Nor did it find any conflict between the work done by the two Centres; it considered that their work is complementary.

The review panel did not identify any specific concerns in relation to the Centres’ implementation of the recommendations of the 1997 quinquennial review.

The review panel noted some priorities for HIV social research for Australia in the next five years. The Strategy Research Review Team considers that the priority-setting process for HIV social research needs improvement and recommends that the priorities identified in the 2002 quinquennial review report be used to assist with this.

The two Centres have been exemplary in involving the affected communities in priority setting for their research, as well as providing information about the outcomes of the research. The Directors and staff of both Centres are involved in several national advisory committees. The Strategy Research Review Team considers, however, that the Centres could improve their processes for informing the advisory structure and government of the content of the research, its significance for policy, and the importance of undertaking it.

The review panel was satisfied that all the recommendations of the 1997 quinquennial review of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society have been met.

**Recommendation 92**

That the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society be congratulated for their high-quality, internationally recognised work in HIV social research.

Hepatitis C research

Both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society have done some hepatitis C research within their core funding and have done other hepatitis C research using other funding sources. The Strategy Research Review Team notes that, with no new allocation for hepatitis C research in the core funding, it will be difficult for the Centres to do significant work in this area without impinging on their HIV research.
The Review Team acknowledges the importance of developing close links with injecting drug users in order to do high-quality social research in this group, even though this is difficult to achieve. The Australian Research Centre in Sex, Health and Society is to be congratulated, however, for its success in this regard and for its commitment to involving the affected communities in work on hepatitis C and injecting drug use. The Review Team also acknowledges that other research centres, such as the National Centres on Drug Research—the National Drug Research Institute, the National Drug and Alcohol Research Centre, and the National Centre for Education and Training on Addiction—may have considerable expertise in this area, and it recommends stronger links between the National Centres on Drug Research, the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society in carrying out hepatitis C social research. This is particularly important because of the lack of uniformity around Australia in relation to drug use patterns.

Recommendation 93

That—where it is possible, feasible and appropriate—the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society engage with National Centres on Drug Research when doing work relating to injecting drug users.

4.4.3 The National Centre in HIV Epidemiology and Clinical Research

HIV/AIDS research

The review panel for the 2002 quinquennial review of the National Centre in HIV Epidemiology and Clinical Research found that the Centre’s research is of outstandingly high quality and is internationally recognised. The panel’s report is provided as Chapter 7 of this document.

The panel did not find fault with the quality or volume of work done by the Centre in all its areas of activity. In its report the panel listed several important achievements it wanted to highlight, among them the Centre’s outstanding publication record: in the last five years the Centre has published 295 peer-reviewed articles, at least 130 of them appearing in journals with an impact factor of five or greater.

With the exception of four recommendations, as detailed in the 2002 quinquennial review report, the review panel was satisfied with the action taken to respond to the recommendations of the 1997 quinquennial review. Both the review panel and the Strategy Research Review Team consider that the recommendations that have not been implemented in full are either in the process of being implemented or require additional assistance to be implemented.

The Centre uses several mechanisms to engage with affected communities, among them the communities’ representation on the Scientific Advisory Committee and working groups. All the submissions from the affected groups praised the Centre for its work and for involving them in it.

The Centre’s work influences policy and strategy formulation in a number of ways. It publishes an excellent annual surveillance report that summarises the epidemiology of HIV,
hepatitis C and STIs in Australia. The Director and staff of the Centre are involved in a number of national committees and working groups. And, through the clinical trials network, the Centre supports clinical practice and has fostered a unique environment in which its primary care practitioner treats the majority of people living with HIV.

Recommendation 94

That the Director and Deputy Director of the National Centre in HIV Epidemiology and Clinical Research be congratulated for their outstanding achievements in HIV epidemiology, surveillance and clinical research.

Hepatitis C research

With the assistance of a small amount of additional funding, the National Centre in HIV Epidemiology and Clinical Research has been able to incorporate hepatitis C surveillance in its work plan. The recent establishment of the Viral Hepatitis Working Group, in cooperation with the Australian Liver Association, will allow the Centre to expand its expertise in clinical trials to assessment of treatments for both hepatitis B and C. This will greatly augment the Centre’s contribution to hepatitis C research, as well as expanding both national and international capacity in this area.
4.5 FUNDING ARRANGEMENTS

4.5.1 The National Centre for HIV Virology Research

The provision of block funding to the National Centre in HIV Virology Research has been essential for generating a critical mass in HIV virology research in Australia. Funding of this kind has also been very useful in improving networking and cooperation between the various laboratories, thus promoting an interdisciplinary research response. This has resulted in Australia being an international leader in HIV virology.

Previous reviews recommended that the funding and administration of the Centre be transferred to the NHMRC and that in future the Centre’s funds be largely obtained through the competitive funding process. This was not fully implemented, and the Population Health Division still funds and administers the Centre. However, as a result of the 2001 MoU between the NHMRC, ANCAHRD and the Population Health Division, all the National Centres in HIV Research have been able to apply for competitive grant funding for research in areas that do not overlap with those covered by core funding. As a result, laboratories within the National Centre in HIV Virology Research have obtained some competitive funding.

The review panel concluded that continuing to provide block funding for the Centre beyond December 2004 is not appropriate. It reached this conclusion for the following reasons:

♦ An internationally competitive critical mass of HIV virologists has now been established in Australia, so the primary purpose of establishing the Centre has been achieved.

♦ It is inappropriate for the Population Health Division to directly fund basic science research in one field of its endeavours to the exclusion of others if this research is not performing a monitoring or strategic function.

♦ With the exception of the non-innovative but strategic research referred to elsewhere, the style of research undertaken by the Centre—that is, investigator-initiated, innovative research—should be amenable to funding by the NHMRC and other sources.

♦ Block funding may be limiting the amount of funding available for HIV virological research, by virtue of inhibiting the success of competitive grant funding applications. For example, the Centre’s researchers may not be developing the skills required to successfully apply for competitive funding (as evidenced by an unsuccessful NHMRC Program Grant application in 2002). The Centre’s researchers may also not be gaining access to the breadth of funding potentially available to them because of a lack of incentive to do so.

The review panel did, however, consider it essential for the ‘core research’ (monitoring and strategic research)—which is unlikely to be funded through the competitive funding process but is important for the response to HIV—to be funded directly. In its view, this work is best done by leading researchers in HIV virology and immunovirology (many of whom currently form part of the Centre) but some of the necessary expertise may exist outside the Centre. The process for developing the list of core research to be purchased is described in Section 4.9 of this chapter.
The panel also considered it would be necessary to provide funding for a networking function. This function would enable and improve communication between virologists working in the field of HIV and related viruses and promote interdisciplinary research, both within Australia and with other countries. The function could include activities such as fostering an annual meeting or workshop, circulation of newsletters, and other relevant activities.

It is expected that the funds required for these two functions (core research and networking) would amount to about half the funds currently provided to the Centre—that is, about $1.0–1.5 million—although this will need to be more accurately costed after the priorities for the core research have been defined.

The Strategy Research Review Team considers that these two functions do not constitute a National Centre, but rather a ‘national network’. It also considers that the necessary funding should be allocated through a competitive process and that the networking function should be supported in one of the laboratories or institutions where some of the core research functions have already been purchased. Among the selection criteria for funding both the core research and the networking functions might be interest and expertise in communication of research findings, significance and objectives; an ability to network with other scientists in Australia and elsewhere; an ability to link the core research activities with innovative research; and responsiveness to the needs and priorities identified by the Department of Health and Ageing together with its advisory structure.

The Review Team does not consider it part of its brief to make recommendations about the process for allocating this competitive funding. The Population Health Division may not have the expertise needed to evaluate the scientific merit of the applications, although it may be well placed to evaluate in terms of the other selection criteria. A process involving the NHMRC, the Population Health Division and the advisory structure may therefore be the most suitable. However, the advantage of the Population Health Division maintaining a funding role is that this would streamline communications between the Department and members of the national network, as well as increase the ‘leverage’ of the Department in ensuring the network’s responsiveness.

The only research that would be funded through this process is core research, so it should then be possible for researchers funded to do this work to have unrestricted access to competitive funding processes. The Population Health Division and ANCAHRD should begin discussions with the NHMRC as soon as possible to ensure that these restrictions on accessing competitive funding processes are lifted.

The Strategy Research Review Team wants to make it very clear that the recommendation to discontinue funding for the National Centre in HIV Virology Research does not reflect a lack of confidence in the Centre’s research quality or the capabilities of the researchers involved. On the contrary, it could be argued that this recommendation is made on the basis of the success of the Centre’s research and the fact that its international competitiveness means that obtaining competitive funding should not be difficult. The researchers may not be accustomed to applying for NHMRC and other competitive funding, and they should be supported in doing so. The following are examples of how this could be done:

♣ If the decision is made to terminate the block funding of the Centre at the end of December 2004 (or sooner), this should be communicated to the Centre as rapidly and as clearly as possible.
♦ The Centre’s researchers should be encouraged to make joint funding bids for core research activities and for the networking function.

♦ In order to hone their skills in applying for funding from NHMRC Program Grants, the Centre’s researchers could ‘team up’ with researchers who have been successful in obtaining such funding.

♦ Details of other funding sources, such as US National Institutes of Health grants, could be obtained from the relevant sources.

Recommendation 95
That block funding for the National Centre in HIV Virology Research cease at the end of December 2004.

Recommendation 96
That a process be developed and funds be identified for purchasing ‘core research’ in HIV virology and immunovirology.

Recommendation 97
That a process be developed and funds be identified for purchasing a networking and communication function for research in HIV virology and immunovirology and that this function be placed with one of the laboratories or institutions that has received funding for the core research.

Recommendation 98
That there be no restrictions on National Centre in HIV Virology Research researchers applying for NHMRC or Australian Research Council funding as a result of receiving funding for core research or the networking function.

Recommendation 99
That the researchers currently involved in the National Centre in HIV Virology Research be encouraged to apply jointly for funding for the ‘core research’ and networking function.
Recommendation 100

That the researchers currently involved in the National Centre in HIV Virology Research be supported and encouraged to develop expertise in obtaining competitive funding to pursue innovative investigator-initiated research.

4.5.2 The National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society

Both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society have produced internationally recognised, high-quality social research. Importantly, this has been possible partly because of the development of close relationships with affected communities and regular liaison with these groups. In turn, these close relationships have allowed a transfer of knowledge that has led to the development of successful prevention strategies. Although this has, to a degree, impeded the Centres’ ability to publish in the peer-reviewed literature, the Centres have still managed to develop a significant portfolio of publications in the peer-reviewed literature. The Strategy Research Review Team considers that these relationships and the liaison process are basic functions of the two Centres and that they make a significant contribution to the infrastructure that is necessary to support social research in this area.

The review panel considered that the current funding arrangements for both Centres have resulted in excellent value for money. This is a result of the quality of the research that has been done, the engagement with affected communities, the dissemination of the research results, and the ability of both Centres to attract considerable outside funding to supplement their research. The review panel also considered that the work done under the block funding arrangements has met some of the strategic needs of the National HIV/AIDS Strategy and, to a lesser extent, the National Hepatitis C Strategy. In its view, the work would largely be considered core research, defined as monitoring or strategic research that would be unlikely to be funded through competitive funding processes. The panel also considered that the community liaison functions undertaken by both Centres represent an essential activity but one that would be unlikely to obtain funding from elsewhere.

Submissions to the review almost uniformly supported these conclusions. Some stakeholders, however—particularly those from outside Sydney and Melbourne—considered that the Centre’s current research does not meet their needs. It was also recognised that the smaller states and territories do not have the funds to purchase research that would meet local needs where these might differ from those associated with the main focus of the epidemic, in Sydney and Melbourne. The review panel considered that these were problems that should not be overlooked. It noted that the work of both Centres would benefit from more strategic planning and that this planning should involve all the relevant stakeholders. The Strategy Research Review Team outlines a process for this planning in Section 4.9.

The review panel was also concerned that the expertise in HIV social research is currently focused in Sydney and Melbourne. The disadvantage of this is that it may limit the Centres’ ability to respond to changes in the epidemic or to other matters, such as hepatitis C and STIs. This is because the Centres may not have had the opportunity to build relationships with affected communities elsewhere. The review panel noted that the expertise needed for high-quality social research in the area of HIV and STIs might not exist outside the two Centres.
The Strategy Research Review Team would therefore encourage both Centres to foster the development of expertise in other parts of Australia, through collaborative projects and mentoring.

Both Centres have strong links with their host universities. This is an essential component of their sustainability, particularly as they grow. It would appear that the support from the host university for the Australian Research Centre in Sex, Health and Society is stronger than that from the host university for the National Centre in HIV Research: the former has been provided with tenure for its senior researchers and is likely to soon receive support for 50 per cent of the Director’s salary. The Review Team acknowledges, however, that the University of New South Wales (the host institution for the National Centre in HIV Social Research) has recently made a commitment to increase its support for the Centre and strongly supports this.

The Review Team therefore considers that the Population Health Division should continue to fund both Centres to current funding levels for at least the next five years. It also considers, however, that a new process should be developed to set the research priorities and that a more open process should be developed for seeking competitive funding for other priority research. (These processes are outlined in Section 4.9.) The Review Team also examined the question of whether the Population Health Division should continue to fund the Centres directly or whether funding should be provided through a body such as the NHMRC or the Australian Research Council. While acknowledging that this is a matter for the Department, the Team cannot see any advantage in transferring this responsibility to another body. If the Department does decide to transfer funding responsibility to another body, however, the Team considers that the following conditions should be maintained:

♦ an ability for the advisory structure and the Department to directly discuss with the Centres their work plans as related to the funding

♦ an ability for the advisory structure and the Department to set the research priorities for the Centres

♦ an ability for the Centres to provide to the advisory structure, the Department and other stakeholders feedback on the results and significance of their work

♦ minimal disruption to the work of the Centres

♦ an assurance that any assessment process for the Centres would involve the expertise necessary for evaluating social research.

It was the review panel’s view that the funding for the two Centres should continue only so long as HIV is a priority for the Department. Should there be changes in the nature of the epidemic as a result of successful vaccine development or a cure, the Department might decide that HIV is no longer a priority. Nevertheless, the panel did not see this as likely to happen within the next decade.

Recommendation 101

That the Population Health Division of the Department of Health and Ageing continue to fund the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society for at least the next five years—initially, through a new five-year funding agreement.
Recommendation 102
That a new process for determining the research priorities of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society, drawing in other researchers and stakeholders, be developed.

Recommendation 103
That both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society be encouraged to nurture social research outside Sydney and Melbourne through collaborative projects and mentoring. This would include developing HIV social research expertise outside the two major Centres.

Recommendation 104
That both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society—and the former in particular—pursue their host universities for increased support, in recognition of the kudos they bring to their hosts.

Recommendation 105
That the processes of funding and administering the funding of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society remain with the Population Health Division of the Department of Health and Ageing. Should the Department choose to transfer this function to another body, however, the conditions specified in recommendations 101 to 104, and any others that may be identified by the advisory structure in consultation with the two Centres, should still be met.

4.5.3 The National Centre in HIV Epidemiology and Clinical Research

The Strategy Research Review Team considers that the current funding arrangement for the National Centre in HIV Epidemiology and Clinical Research is efficient, cost-effective and appropriate. The Centre has been able to expand its research income many times over by attracting funding from other sources, including overseas; this has facilitated the Centre’s expansion to 70 staff, with significant research output. The overseas research funding includes a significant National Institutes of Health grant for a vaccine initiative; this funding is being shared between a number of research bodies in Australia (including the National Centre in HIV Social Research and the National Centre in HIV Virology Research), with the goal of developing and trialling an HIV vaccine. The funding provided to the Centre through the block funding arrangements is used almost exclusively for core research—monitoring or strategic research that would be unlikely to attract funding from other sources but that is a priority for the National HIV/AIDS Strategy. The funding is also used to provide infrastructure to enable the research to be done; examples of this are the clinical trials network and the Australian HIV Observational Database. The Centre’s strong international
standing and its history of engaging with clinicians, researchers and epidemiologists, throughout the country and internationally, are further evidence that the current funding arrangement is suitable and cost-effective.

Within its Terms of Reference and current priorities, the Centre is meeting the research needs of its disciplines. The review panel recommended, however, that the Centre make use of or obtain expertise in anti-retroviral pharmacology, to extend the reach of its clinical research. The Centre should be encouraged to do this. The Centre’s ability to acquire expertise in a number of areas that are central to its work is a good example of how providing support for core research through block funding can enable the acquisition of funding for other priority research through competitive sources.

Both the review panel and the Strategy Research Review Team consider that the Centre should be better supported by its host institution, the University of New South Wales, especially since the Centre is a flagship for the University. The University has indicated a willingness to review its level of support, with view to increasing that support in the future. This is important for the Centre’s sustainability.

The Review Team notes the opportunities for the Centre to expand its role in a number of related areas. It is already extending its surveillance capacity to hepatitis C and STIs, and it would be worthwhile exploring with the Communicable Diseases Network Australia ways in which Australia’s surveillance capacity in other communicable diseases might be expanded with the Network’s support. The Centre is already involved in aspects of Creutzfeldt–Jakob disease surveillance and, with its future involvement in clinical trials involving hepatitis B and C, it is expanding its reach in this area. There may, however, be opportunities to also extend its expertise in clinical trials in the primary care setting to other conditions of public health importance, possibly through providing training and support for other groups to do similar work in other areas.

The Centre currently receives a small amount of additional funding for hepatitis C surveillance. The Review Team recommends that this funding be continued and that it be rolled into the Centre’s core funding.

The Review Team therefore recommends that the Centre continue to be funded through a block funding arrangement for at least five years. The funding should not be expected to continue indefinitely; it would be expected to cease when HIV is no longer a priority for the Department. Such a scenario could be expected to arise if an effective vaccine or cure, or both, were developed, but this does not seem imminent.

The Review Team considers that the current funding arrangement for the Centre—through the Population Health Division—is the best way of administering the funds. This is because the funds are being used to support core public health activity and because the current arrangement appears to be working well. If the Department decides to transfer the funding process to another body, however, the Review Team considers that the following conditions should be maintained:

- an ability for the advisory structure and the Department to directly discuss with the Centre its work plan as related to the funding

- an ability for the advisory structure and the Department to set the research priorities for the Centre
♦ an ability for the Centre to provide to the advisory structure, the Department and other stakeholders feedback on the results and significance of its work

♦ minimal disruption to the work of the Centre.

**Recommendation 106**

That the Population Health Division of the Department of Health and Ageing continue to fund the National Centre in HIV Epidemiology and Clinical Research for at least the next five years—initially, through a new five-year funding agreement.

**Recommendation 107**

That the National Centre in HIV Epidemiology and Clinical Research pursue its host university for increased support, in recognition of the kudos it brings to its host.

**Recommendation 108**

That the National Centre in HIV Epidemiology and Clinical Research explore ways of expanding the reach of its expertise—particularly in communicable diseases surveillance and in conducting clinical trials in the primary care setting—into other areas of concern to the Population Health Division.

**Recommendation 109**

That the Population Health Division continue to provide the National Centre in HIV Epidemiology and Clinical Research with additional funds for hepatitis C surveillance and that these funds be rolled into the Centre’s core funding.

**Recommendation 110**

That the processes of funding and administering the funding of the National Centre in HIV Epidemiology and Clinical Research remain with the Population Health Division. Should the Department choose to transfer this function to another body, however, the conditions specified in recommendations 106 to 109, and any others that may be identified by the advisory structure in consultation with the Centre, should still be met.
4.6 HEPATITIS C RESEARCH

All stakeholders, including the Population Health Division, recognise that incorporation of hepatitis C research in the core HIV research agenda has not been successful in meeting the strategic research needs of hepatitis C, with the exception of a few small areas. Although there are areas of overlap between HIV and hepatitis C research, there are important areas where the research agendas do not overlap. Further, even carrying out research in overlapping areas can require additional resources, but very few extra resources have been provided for hepatitis C research in Australia.

The formation of the Australian Viral Hepatitis C Centre is an important initiative in developing hepatitis C viral research. While it is not currently supported by block funding, additional support will increase the Centre’s capacity to pursue important hepatitis C virological research.

Australia’s experience in managing HIV demonstrates the importance of research as the basis for a successful response. This is reflected in both the National HIV/AIDS Strategy and the National Hepatitis C Strategy.

The Review Team also points out that, as with HIV research, engagement of the affected communities in determining research directions and communicating research results is essential to the success of the research endeavour.

As noted, funding of $1 million for the NHMRC’s Strategic Research Development Committee’s Social and Behavioural Research Program into Hepatitis C was allocated from the Committee’s own budget in 1998. The funded projects have yielded useful results, but their short-term nature meant that it was not possible for strategic engagement of researchers with the issues pertaining to hepatitis C. This is not mentioned as a criticism of the Strategic Research Development Committee; rather, it is to point out that a sustained research response requires sustained funding. The Review Team considers that, in order to be successful in meeting public health needs, hepatitis C research should focus on specific priority areas and should build up over time.

The Review Team explored ways in which hepatitis C research could be encouraged in Australia. At present the Australian Research Council and the NHMRC each have a new funding model that offers significant funding for a program of research over a five-year period. Partners contribute funding to the research effort and participate in defining the research agenda. In both of the models—called Discovery funding by the Australian Research Council and Partnership funding by the NHMRC—each organisation can contribute funds. Since funding for hepatitis C research comes within the remit of both the NHMRC and the Australian Research Council, there is potential to develop a partnership between the NHMRC, the Australian Research Council, the Population Health Division and other stakeholders in funding hepatitis C research. This could also provide a very good model for funding other areas of population health. The partnership, which can involve others who do not necessarily contribute funds to research (for example, the community sector), is also responsible for setting the strategic direction of the research program and monitoring its outcomes.

The NHMRC and the Australian Research Council also provide funding for new researchers, to encourage them to take up research in particular areas. This is another potential source of funding for hepatitis C research that should be explored further.
Recommendation 111

That strategic hepatitis C research be acknowledged as central to the Australian response to hepatitis C. Processes should be set up and resources allocated accordingly.

Recommendation 112

That the Population Health Division explore with the NHMRC and the Australian Research Council ways of funding a program of hepatitis C research over a long-term time frame, such as through Partnership funding.
4.7 RESEARCH INTO INDIGENOUS AUSTRALIANS’ SEXUAL HEALTH

As in other areas of public health, research has been integral to the development of strategies for responding to concerns in relation to the sexual health of Indigenous Australians, as well as hepatitis C in this population. Although both the Australian Research Centre in Sex, Health and Society and the National Centre in HIV Epidemiology and Clinical Research have been involved in research or surveillance of importance to Indigenous Australians’ sexual health, the subject has not been a strong research focus for any of the Centres. The Mapping Indigenous Risk project funded by the Department of Health and Ageing was an important initiative in which key research questions were identified. In order to develop a strong research response, however, it is necessary to develop a critical mass of research expertise in Indigenous sexual health and in hepatitis C.

The Review Team considers that the NHMRC funding model for research through the competitive grant processes has not been successful in engendering the research response required in this area. This is possibly because a number of the research questions are not ‘innovative’, because sometimes research questions in Indigenous sexual health need to be defined by the communities involved, and because some of the other criteria for assessing research grant applications may not be suited to evaluating research in Indigenous sexual health and hepatitis C. This may also be a problem for research in other areas relating to Indigenous health. In addition, other important initiatives in the area of Indigenous health research have been introduced in order to respond to these and other issues. The Review Team considers, however, that opportunities to build a critical mass of expertise in research into Indigenous Australians’ sexual health should be explored. The new funding models developed by the NHMRC and the Australian Research Council—involving a partnership approach, as described in Section 4.6—may also be relevant here.

Recommendation 113

That the Department of Health and Ageing explore ways in which research into the sexual health of Indigenous Australians, as well as hepatitis C and HIV in this population, can be supported and funded through appropriate mechanisms, taking the lead from the current reform agenda in Aboriginal research that is being developed nationally.
4.8 INTERNATIONAL HIV RESEARCH

The 1997 quinquennial reviews of both the National Centre in HIV Social Research and the National Centre in HIV Epidemiology and Clinical Research recommended that the Centres extend their area of research internationally, particularly in the Asia–Pacific region, which is of critical importance to Australia. This recommendation is consistent with the fourth National HIV/AIDS Strategy. Both Centres, as well as the Australian Research Centre in Sex, Health and Society, have carried out some research in the Asia–Pacific region, and it is recognised that the vaccine initiative (see Chapter 7) will require additional social and epidemiological research in order to prepare for a phase III vaccine trial. However, the difficulty of obtaining funding constitutes an important barrier to doing HIV research in the region. This means that the expertise developed in the Centres has not been used to benefit the region to the fullest extent.

The 1997 review of the National Centre in HIV Epidemiology and Clinical Research recommended that the Department develop a dialogue with AusAID in order to explore mechanisms whereby AusAID might support the work of the Centres in the Asia–Pacific region. To date, however, this has not resulted in an appropriate funding stream. Recent restructuring within AusAID might open doors for further discussions of this matter, so the Review Team recommends that such a dialogue be resumed.

The Review Team also considers that there are opportunities for the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society to make significant contributions to HIV social research in the region. Researchers not involved in the National Centres also have contributions to make.

The NHMRC’s recent announcement of collaboration with the Wellcome Trust to fund the work of Australian researchers overseas also provides an opportunity to extend the reach of Australian HIV researchers into the Asia–Pacific region.

Recommendation 114

That the Population Health Division resume dialogue with AusAID with a view to obtaining funding support for Australian researchers to work in HIV-related research in the Asia–Pacific region.
4.9 FUTURE SYSTEMS FOR SUPPORTING STRATEGY RESEARCH IN HIV/AIDS, HEPATITIS C AND RELATED DISEASES

The Strategy Research Review Team agrees that, although Australia’s research effort in HIV/AIDS has been exemplary, there is a need to strengthen the links between the research effort and policy and implementation. Stakeholders should be more involved in setting the research agenda. There also needs to be a much stronger process for reviewing the research results and assessing their implications for policy and practice. Several important gaps in the current research effort were identified during the review.

The Review Team is also aware that there is important research done in Australia that is relevant to the National HIV/AIDS Strategy and the National Hepatitis C Strategy but that falls outside of the Centres. This research is even less likely to be influenced by national priorities or to influence policy and practice, since there is at present no satisfactory mechanism for doing so. Finally, important research is being done internationally but its significance may not be reflected in the policy agenda.

These problems were recognised on a broader level in the 1999 Health and Medical Research Strategic Review report, *The Virtuous Cycle—working together for health and medical research*, known as the Wills report. Although the NHMRC should be commended for its efforts to date, it has not made sufficient progress in dealing with these problems. The Review Team also considers that the Population Health Division has some role in developing or harnessing the expertise to gain access to and interpret research information relevant to its area of responsibility. This might involve developing within the Division a critical mass of expertise that is capable of interpreting research in the different disciplines relevant to public health in Australia, including HIV/AIDS. Another possibility would be to obtain this expertise within the advisory structure for HIV/AIDS and related diseases, although this would have the disadvantage of being small and therefore not being able to sustain an active and able workforce.

Many of the stakeholders who contributed to this review were of the opinion that the current advisory structure creates a division between the research and policy areas that is not conducive to the development of stronger links between policy and research. Specifically, some stakeholders recommended that the Clinical Trials and Research Committee of ANCAHRD be disbanded and that its research expertise be incorporated in the HIV, Hepatitis C and Indigenous Sexual Health Sub-committees. Some stakeholders also expressed the view that the current overarching body, ANCAHRD, provides a confusing structure, where some of the important views of the Sub-committees are lost. The Review Team agrees. It therefore recommends a revised advisory structure, in which there are three committees—HIV/AIDS, Hepatitis C and Indigenous Sexual Health—that each contain expertise in policy and research as well as the relevant community sector. The person chairing each committee should have expertise in either policy or research and the deputy chair should have expertise in the other area. The overarching body would then consist only of the chairs and deputy chairs of the three committees, with or without an independent chair. Its role should be to act largely as a conduit for communication between the three committees, as well as being a convenient mechanism for communication between the advisory structure and outside agencies.
The Review Team considers that the advisory structure should play a central part in setting
the research agenda but that it should not be responsible for this alone. Rather, the Team
recommends a triennial process for setting research priorities for the next three years. This
process should involve all key stakeholders, including the advisory structure and researchers
themselves, and could take the form of a workshop (or series of workshops) that would,
among other things, review the research that has been done in the preceding three years. The
outcome should be a list of research priorities, in order of importance, for each area of work
(that is, HIV/AIDS, hepatitis C and Indigenous sexual health) and each discipline (that is,
social research and epidemiology). This list of research priorities should be widely
distributed, with a view to influencing the work done by researchers seeking funding through
the competitive grant process as well as the Centres. The list of priorities should also be
presented to the NHMRC and the Australian Research Council and be used by grant assessors
to assess the significance of research grant applications in the areas of HIV/AIDS, hepatitis C
and Indigenous sexual health.

The Centres should develop a three-year strategic plan in response to these research
priorities; the plan should detail the research to be funded through the Centre’s core funding
as well as through other sources. They should also be encouraged to use the list of research
priorities to collaborate with other groups and apply for competitive research funding to meet
the priorities. Where possible, the Centres should seek competitive funding to meet the
research priorities, their core funding being used to fund areas of research that are of the
highest priority and/or are unlikely to be funded through competitive processes. Each year the
Centres would then provide the Population Health Division (or their funder) with a costed
work plan relating to their core funding. The plan would be forwarded to the advisory
structure for information and to provide an overview of the full research agenda undertaken
by the Centres. This would ensure that there is no overlap between the work of the different
Centres and no significant gaps in research activity.

If this procedure were followed, the Review Team considers it would obviate the need to
review all NHMRC grant applications by the Centres for overlap with their core-funded
research, as happens at present. The current process does not represent an efficient use of
resources and also may inhibit the Centres’ creativity as a result of micro-management and
confusion about procedure. As with its recommendation for basic virology research,
therefore, the Review Team recommends that the Population Health Division, the advisory
structure and the NHMRC review the funding processes with a view to eliminating the need
to restrict competitive funding of research undertaken by the Centres.

The Review Team also considers that the role of the Centres’ Scientific Advisory
Committees should be strengthened. These Committees would have a key role in developing
the work plans of the Centres, and the Population Health Division would have input into the
work plans largely through membership of the Committees. Further, the Scientific Advisory
Committees should play a central role in monitoring the Centres’ progress against the work
plans and assessing and communicating the implications of the research. The Scientific
Advisory Committees would be mandated to cover the core funded research, but there would
be strategic value in them looking at this research in the context of the Centres’ broader
research programs. This broader role goes beyond that of a ‘Scientific Advisory Committee’,
and the Review Team therefore recommends that the Committees be renamed—for example,
Scientific and Strategic Steering Committee—to reflect this broader role.
Recommendation 115

That the Population Health Division explore ways of accessing research expertise to assist with the management of a research program, including developing priorities for research and translating the research results into policy and practice.

Recommendation 116

That the Clinical Trials and Research Committee of ANCAHRD be abolished and a revised advisory structure be formed, with HIV/AIDS, hepatitis C and Indigenous sexual health committees having a mixture of policy and research expertise. The advisory structure’s overarching body should have only minimal influence on the work of these committees.

Recommendation 117

That there be a triennial time frame for setting research priorities in the areas of HIV/AIDS, hepatitis C and the sexual health of Indigenous Australians. All the relevant stakeholders should be involved in deciding the priorities, and the process should include a review of research undertaken to that time.

Recommendation 118

That the research priorities determined for each three-year period be communicated to the NHMRC and the Australian Research Council, with a view to influencing funding decisions. The priorities should be used to assess the significance of competitive grant applications in the areas of HIV/AIDS, hepatitis C and Indigenous Australians’ sexual health.

Recommendation 119

That, wherever possible, competitive funding sources be used for funding priority research and that core funding provided to the Centres be used for research that is of the highest priority and/or would be unlikely to be funded through competitive processes.

Recommendation 120

That the NHMRC, the advisory structure replacing the Clinical Trials and Research Committee, and the Population Health Division of the Department review the practice of restricting competitive grant applications by the Centres, with a view to removing the restrictions in the light of the processes recommended here.
Recommendation 121

That the role of the Centres’ Scientific Advisory Committees be strengthened and broadened to include overseeing, monitoring and communication tasks. The name ‘Scientific Advisory Committee’ might need to be changed to reflect this.
4.10 APPENDIX A  TERMS OF REFERENCE

The following Terms of Reference were issued for the 2002 review of the National Centres in HIV Research, the Strategy Research Review and the discipline-specific review panels.

A.1 The 2002 Review of the National and Collaborating Centres in HIV Research

Preamble

This review will focus on assessing the scientific quality and international competitiveness of the research effort conducted at the Centres in HIV Research under the National HIV/AIDS Strategy 1999–2000 to 2003–04, Changes and Challenge; the National Indigenous Australians’ Sexual Health Strategy 1996–97 to 1998–99; and the National Hepatitis C Strategy 1999–2000 to 2003–04. This review is conducted within the context of Australia’s system of funding health and medical research (including the application of research to public health and health care). The overall purpose of the review is to ascertain the effectiveness of the current Centres in supporting research required to deliver Strategy objectives and to develop recommendations about the best method or structure for supporting strategy research.

The reviews of the National HIV/AIDS and Hepatitis C Strategies

The proximity of the timing of the quinquennial review with the reviews of the current National HIV/AIDS and Hepatitis C Strategies (due to commence in 2002/2003), will provide the opportunity the former to be an adjunct to the latter. In this way the recommendations arising from the quinquennial review will not only inform the future of HIV/AIDS and hepatitis C research arrangements but will also inform the respective National Strategy reviews.

Hepatitis C research

It is acknowledged that the Centres were established and funded under the National HIV Strategies. With regard to hepatitis C research, the current Hepatitis C Strategy was launched in June 2000 without specific funding for implementation and the hepatitis C activities of Centres have arisen out of specific negotiations with the Department of Health and Ageing.

Mainstreaming and the 2001 Administrative Review of National Centre in HIV Virology Research

The former Federal Health Minister, the Hon Dr Michael Wooldridge, stated that strategy research will continue to be funded through the Population Health Division until the end of 2003, but non-strategy research is to be ‘mainstreamed’—that is, to compete for funding through the NHMRC grants system. A MoU between the Population Health Division, ANCAHRD and the NHMRC to establish arrangements and relevant time frames to allow a smooth transfer of responsibilities and research funding to 2003 has now been signed.

In 2001 an administrative review of the National Centre in HIV Virology Research was undertaken in the context of facilitating a successful ‘transfer of funding of the National Centre in HIV Virology Research to the NHMRC’. This review was undertaken by a committee chaired by Dr Janice Hirshorn, with the final report being submitted to the Clinical
Trials and Research Committee and the Department of Health and Ageing on 20 August 2001. The final report of this review will inform the 2002 quinquennial review and will very likely result in a reduced submission being required from the National Centre in HIV Virology Research.

A.2 The Strategy Research Review Team

In the context of assessing the scientific quality and international competitiveness of research, the Strategy Research Review Team 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 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 (ie 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 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—that is, competitive application, contracting and/or commissioning
   – systems for monitoring strategy research to achieve objectives of quality and relevance
   – systems through which strategy advisory bodies (such as ANCAHRD), the NHMRC, the Australian Research Council and other Australian government research funding agencies can interact to discuss specific research priorities and programs.
## 4.11 APPENDIX B

### THE 2002 STRATEGY RESEARCH REVIEW: PROGRAM OF STAKEHOLDER INTERVIEWS

<table>
<thead>
<tr>
<th>Time</th>
<th>Stakeholder</th>
<th>Representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday 3 June</td>
<td></td>
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</tr>
<tr>
<td>1430–1500</td>
<td>Department of Health and Ageing</td>
<td>Greg Sam (Assistant Secretary, Communicable Diseases &amp; Health Protection Branch)</td>
</tr>
<tr>
<td>Tuesday 4 June</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0930–1030</td>
<td>Australian Research Council</td>
<td>Douglas McEachern (Executive Director, Social Sciences)</td>
</tr>
<tr>
<td>1100–1130</td>
<td>Assoc. Prof. Nick Crofts, Burnet Institute (by phone)</td>
<td></td>
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<tr>
<td>1130–1200</td>
<td>University of New South Wales</td>
<td>James Walsh (Director, Research Office)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prof. David Cooper (Director, NCHECR)</td>
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<tr>
<td></td>
<td></td>
<td>Prof. John Kaldor (Deputy Director, NCHECR)</td>
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<tr>
<td></td>
<td></td>
<td>Prof. Sue Kippax (Director, NCHSR)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bronwen Turner (Manager, Finance &amp; Administration, NCHECR)</td>
</tr>
<tr>
<td>1200–1330</td>
<td>Melbourne University</td>
<td>John Gorry (Departmental Manager)</td>
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<tr>
<td></td>
<td></td>
<td>Prof. Roy Robbins-Browne.</td>
</tr>
<tr>
<td>1330–1400</td>
<td>Australian Liver Association</td>
<td>Prof. Geoff McCaughan (Director, AW Morrow Gastroenterology &amp; Liver Institute Centre, Royal Prince Alfred Hospital)</td>
</tr>
<tr>
<td>1400–1430</td>
<td>Australasian Society for HIV Medicine</td>
<td>Levinia Crooks (Executive Officer)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assoc. Prof. Andrew Grulich (President)</td>
</tr>
<tr>
<td>1430–1500</td>
<td>Australian Hepatitis Council Australian Injecting and Illicit Drug Users League</td>
<td>Jack Wallace (Executive Officer)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tamara Speed (President)</td>
</tr>
<tr>
<td>1630–1700</td>
<td>ANCAHRD</td>
<td>Chris Puplick (Chair, ANCAHRD)</td>
</tr>
<tr>
<td>Wednesday 5 June</td>
<td></td>
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</tr>
<tr>
<td>1330–1400</td>
<td>National Centre in HIV Virology Research</td>
<td>Prof. Tony Cunningham (Deputy Director)</td>
</tr>
<tr>
<td>1400–1430</td>
<td>National Centre in HIV Epidemiology and Clinical Research</td>
<td>Prof. David Cooper (Director)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prof. John Kaldor (Deputy Director)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bronwen Turner (Manager, Finance &amp; Administration)</td>
</tr>
<tr>
<td>Time</td>
<td>Organisation</td>
<td>Officials</td>
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<tr>
<td>--------</td>
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<td>---------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 1430–1500 | National Centre in HIV Social Research          | Prof. Sue Kippax (Director)  
Dr Paul Van de Ven (Deputy Director) |
| 1500–1530 | Australian Research Centre in Sex, Health and Society | Prof. Marian Pitts (Director)  
Assoc. Prof. Gary Dowsett (Deputy Director) |
| 1600–1700 | Australian Federation of AIDS Organisations (AFAO); National Association of People Living With HIV/AIDS (NAPWA) | Don Baxter (Executive Director, AFAO)  
Phillip Medcalf (President, NAPWA)  
Peter Canavan (National Treatments Portfolio Convenor, NAPWA) |
| 1700–1800 | ANCAHRD                                         | Dennis Altman (Deputy Chair, HIV Committee)  
Prof. Robert Batey (Chair, Hepatitis C Committee)  
Prof. Cindy Shannon (Chair, Indigenous Australians’ Sexual Health Committee)  
Prof. Peter McDonald (Chair, Clinical Trials and Research Committee)  
Apology: Chris Puplick (Chair, ANCAHRD Executive) |
2002 QUINQUENNIAL REVIEW OF THE NATIONAL CENTRE IN HIV VIROLOGY RESEARCH

Professor Rodney E Phillips
Emeritus Professor Ed G Westaway
Professor Tony Basten
5.1 SUMMARY AND RECOMMENDATIONS

5.1.1 Summary

Since its inception the National Centre in HIV Virology Research has been involved in internationally competitive research. A number of members of the Centre have established international reputations in the field of HIV/AIDS and the consortium represents a major asset to Australian medical science.

The Melbourne-based laboratories’ relocation to the Alfred Hospital site and the new prospects for close collaboration with clinicians at the Burnet Institute for Medical Research and Public Health (formerly the Macfarlane Burnet Centre) and the Alfred Hospital are exciting developments.

The current transitional arrangements for funding require scientists in the Centre to apply for personal Fellowships as well as project and program support in the competitive environment of the NHMRC system. The resignation of the Director of the National Centre in HIV Virology Research, Professor John Mills, necessitates the appointment of an interim Director, who should work closely with the newly appointed Director of the Burnet Institute to support the National Centre in HIV Virology Research scientists during this time.

The continuing global threat of HIV/AIDS—with its evolving biological characteristics—provides a compelling argument for Australia to retain the technical capacity to study the virology of HIV/AIDS at the national level. The Review Panel strongly recommends the continuation of support for a virology and immunology centre in Australia beyond 2003, when current funding ends.

The successful investment in high-level technical capacity for HIV/AIDS virology at the Centre represents a major achievement that can continue to provide a powerful means of investigating the epidemic in Australia and internationally.

5.1.2 Recommendations

The following is recommended:

122. That the National Centre in HIV Virology Research be sustained beyond 2003, with a nodal structure, as part of a strategic approach to the international HIV/AIDS epidemic.

123. That, following the resignation of the current Director, effective 31 December 2002, an interim Director be appointed for the transition period, who will be asked to maintain the scientific excellence at the Centre and to support the scientific staff, in collaboration with the incoming Director of the Burnet Institute.

124. That the interim Director be chosen from among the current principal investigators of the Centre.

125. That new applications for core support of the Centre be opened up for competitive bidding within the wider HIV virology and immunology community.
126. That the appointment of a new Director be incorporated in the new application process.

127. That responsibility for hepatitis C strategy research remain outside the Terms of Reference of the National Centre in HIV Virology Research and that an alternative mechanism be established to earmark funding for hepatitis C virology research.

128. That the HIV virology core research by the Centre be clearly defined, as outlined in this report, and that contracts for provision of this service very clearly describe the work required and the reporting structure.

129. That the role of the Scientific Advisory Committee be strengthened to oversee and monitor both strategic planning and scientific standards, and to provide regular written reports to ANCAHRD.

130. That services provided by the Centre, as outlined in this report, be incorporated in an annual work plan and include support for overseas collaborations and immunovirology monitoring for clinical studies of the molecular characterisation of HIV.

131. That links between this Centre, clinical groups and the National Centre in HIV Epidemiology and Clinical Research be fostered.

132. That Dr Stephen Kent’s formal linkage to the Centre be a priority for the future.

133. That an administrative mechanism be established that allows scientists providing core virology services ‘under contract’ access to peer-reviewed grant support, including from the NHMRC.

134. That administrative arrangements for the Centre beyond 2003 be clearly defined and transparent from the outset.
5.2 THE REVIEW PROCESS

The members of the Review Panel were:

Chair: Professor Rodney E Phillips  
The Peter Medawar Building for Pathogen Research  
Oxford, UK

Members: Emeritus Professor Ed G Westaway  
Sir Albert Sakzewski Virus Research Centre  
Brisbane

Professor Tony Basten  
Centenary Institute  
Sydney

Secretariat support was provided by Dr Robyn Biti, Commonwealth Department of Health and Ageing.

Professor Peter McDonald, Chair of the Clinical Trials and Research Committee of ANCAHRD was available to provide advice.

The Terms of Reference for the review are set out in Section 5.6 (Appendix A).

The Centre was asked to make two written submissions to the Review Panel. The first submission dealt with the Centre’s past achievements in research and training, its contribution to HIV/AIDS Strategy activities, and future goals, particularly in the Strategy area. The second submission was in the format of an NHMRC Program Grant, detailing the Centre’s projects, achievements and future plans.

Three independent experts were asked to assess the Program Grant submission and to rate the Centre’s achievements, research plan, team, and cooperation, as described in the submission. The Director of the Centre had the opportunity to respond to the comments of two of the assessors before the interview.

A number of applications for Project Grants and Fellowships were submitted to the NHMRC in parallel with the Program Grant submission. The Panel received a list of the Project Grant applications but did not have access to the text or the assessors’ reports at the time of interview. In the Panel’s opinion, however, sufficient information was provided in the two submissions to permit a fair assessment of the Centre’s performance.

Public submissions dealing with the Centre’s operations were sought from stakeholders and interested parties. Written submissions were received from:

♦ the Victorian Department of Human Services
♦ the Australian Federation of AIDS Organisations
♦ the Australian Hepatitis Council
♦ the Australian Liver Association of the Gastroenterological Society of Australia
♦ the National Association of People Living with HIV/AIDS
♦ the Australasian Society for HIV Medicine
♦ the Australian Injecting and Illicit Drug Users League
♦ the Australian Red Cross Blood Service
♦ People Living with HIV/AIDS (NSW) Inc.
♦ the Burnet Institute for Medical Research and Public Health Ltd (Dr N Crofts)
♦ the Office for Aboriginal and Torres Strait Islander Health.

These submissions were available to the Review Panel at the time of interview.

The Review Panel met with the Centre’s principal investigators on Monday 2 June 2002 and continued its deliberations on Tuesday 3 June. It also interviewed Professor Steve Wesselingh, the incoming Director of the Burnet Institute; Professor Jim McCluskey, representing the University of Melbourne; Ms Susan Best, Senior Scientist at the National Serology Reference Laboratory; and Dr Stephen Kent.

The draft report containing the Review Panel’s recommendations was submitted by the Chair, Professor Rodney Phillips, to the Strategy Research Review Team on Wednesday 4 June 2002; this was followed by a complete report in mid-June.
5.3 BACKGROUND

5.3.1 Preamble

The National Centre in HIV Virology Research was created in 1986, as the NHMRC Special Unit in HIV Virology; it was renamed in 1989. Its founding Director was Professor Ian Gust, who left the position in 1990. Professor Ed Westaway acted in the role until November 1992, when the present Director, Professor John Mills, took up his appointment. The 1992 Review Panel recognised that the uncertainty caused by management changes and annual funding arrangements should be rectified, and on its recommendation the Centre was funded for five years, with provision for review in the fourth year. The 1997 Review Panel noted the exceptionally high-level performance of the Centre in the preceding five years and unequivocally recommended the continuation of the funding agreement, to include another five years of stable funding, due to expire at the end of 2003.

5.3.2 Inclusion of hepatitis C

In an effort to deal with the rapidly growing threat of hepatitis C virus in Australia, and in recognition of the strong links between the National Hepatitis C Strategy and population health policies dealing with HIV/AIDS, the Commonwealth Government has attempted to encourage incorporation of hepatitis C strategy research in the role of the National Centres in HIV Research during the current funding period. However, the National Centre in HIV Virology Research received no earmarked funding for this hepatitis C component.

5.3.3 Transfer of non-strategy research to the NHMRC

The current funding period has also seen the beginning of a transition to ‘mainstreaming’ of non-strategy research, requiring submission of competitive applications to the NHMRC for funding of investigator-driven research. The National HIV/AIDS Strategy 1999–2000 to 2003–04 defines strategy research as follows:

research into the replication, pathogenesis and transmission of HIV and other viruses that have a clear and direct impact on HIV progression or transmission, to facilitate the development of vaccines, immuno-modulatory agents and antiretroviral drug treatments.

The Review Panel notes that this definition corresponds to only one of the eight points in the Centre’s Terms of Reference (see Section 5.7 (Appendix B)), while three others (points 2, 3 and 6) could also be categorised as strategy research. In the Panel’s view this administrative subdivision has led to a degree of uncertainty among the Centre’s staff on which projects fit where, since any tightly knit program will involve significant overlap between strategy and non-strategy research.

5.3.4 Administration

The Centre is administered through the University of Melbourne and the secretariat is based at the Burnet Institute, which is in the process of moving to new facilities at the Alfred Hospital. In September 2001 a formal MoU was signed by the University and the Centre, and the Centre now receives a substantial share (85 per cent) of infrastructure funds from a
Commonwealth Department of Education, Science and Training grant to the University for its research programs. The Centre is made up of a network of laboratories around Australia, with eight units across five states and territories, as shown in Table 5.1.

Table 5.1 National Centre in HIV Virology Research laboratories

<table>
<thead>
<tr>
<th>Unit</th>
<th>Location</th>
<th>Principal Investigator</th>
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</thead>
<tbody>
<tr>
<td>AIDS Research Laboratory</td>
<td>Sir Albert Sakszewski Virus Research Centre, Brisbane</td>
<td>Dr David Harrich</td>
</tr>
<tr>
<td>Centre for Virus Research</td>
<td>Westmead Millennium Institute, Sydney</td>
<td>Prof. Tony Cunningham</td>
</tr>
<tr>
<td>Genetic Vaccines and Immunobiology Unit</td>
<td>John Curtin School of Medical Research, Canberra</td>
<td>Prof. Ian Ramshaw</td>
</tr>
<tr>
<td>AIDS Pathogenesis Research Unit</td>
<td>Burnet Institute</td>
<td>Prof. Suzanne Crowe</td>
</tr>
<tr>
<td>AIDS Molecular Biology Unit</td>
<td>Burnet Institute</td>
<td>Assoc. Prof. Nick Deacon</td>
</tr>
<tr>
<td>AIDS Cellular Biology Unit</td>
<td>Burnet Institute</td>
<td>Assoc. Prof. Dale McPhee</td>
</tr>
<tr>
<td>AIDS Research Laboratory</td>
<td>Institute of Medical and Veterinary Science, Adelaide</td>
<td>Prof. Chris Burrell, Dr Peng Li</td>
</tr>
<tr>
<td>AIDS Research Laboratory</td>
<td>Hanson Centre, Adelaide</td>
<td>Prof. Matthew Vadas, Prof. Angel Lopez</td>
</tr>
</tbody>
</table>
5.4 PERFORMANCE AND ACHIEVEMENTS

5.4.1 General comments

The Review Panel appreciated the quality of the documentation presented to it by the Director and his colleagues and commends them on a well-planned interview conducted in a professional, cooperative manner. During the interview a number of important matters relating to the Centre’s administration, staff and scientific goals emerged.

Administrative issues

The nodal structure of the Centre has continued to work well and should be preserved in the future, even if the structure undergoes some revision. On the other hand, it is clear that there have been tensions between the Centre, the University of Melbourne, and the Population Health Division of the Commonwealth Department of Health and Ageing, particularly with respect to:

♦ management responsibilities
♦ ‘mainstreaming’ of non-strategy research with the transfer to the NHMRC
♦ the role of the Scientific Advisory Committee.

Some clarity was achieved by the commissioning of the Hirshorn report in 2001 and the more recent signing of a formal MoU between the relevant bodies.

Centre staff

A general concern about future options was evident among the staff; this had affected their confidence and the strategy adopted for grant submissions. In a sense this has been compounded by the recent resignation of Professor Mills from his dual positions as Director of the Burnet Institute and Director of the National Centre in HIV Virology Research. The Panel does not see the apportioning of blame for this situation as part of its remit. Nevertheless, it does wish to draw attention to the importance of Population Health Division and the NHMRC ensuring an equitable transition for the 18 career scientists affected by the mainstreaming exercise.

Scientific goals

The National Centre in HIV Virology Research has proposed expanding the mandate of the Centre to include hepatitis C strategy research, through the inclusion of Professor Eric Gowans. Despite Professor Gowans’ high-quality project on dendritic cell immunotherapy on hepatitis C infection, in the Panel’s opinion, hepatitis C does not sit easily from a scientific perspective alongside retroviruses such as HIV when strategy research is the issue. Although the two diseases are prevalent among overlapping populations, the causative agents are radically different, as are the clinicians responsible for patient care.
5.4.2 Non-strategy research achievements

The Panel was favourably impressed with the quality of the individual basic research projects of Centre staff over the past three years. This was echoed by all three assessors of the Program Grant application, who drew particular attention to:

♦ the strong performance of the Director, Professor John Mills

♦ the internationally recognised contributions of Professors Cunningham and Crowe to the roles of dendritic cells and monocytes/macrophages respectively in HIV immunopathology

♦ the excellent studies of Dr David Harrich on the role of reverse transcription and TAR in HIV replication, and tat mutant strains that have implications for the design of novel anti-retroviral drugs

♦ Professor Ian Ramshaw’s substantial achievements in the HIV vaccine field, particularly the development of the prime boost strategy and the novel SAVINE approach, and his involvement in the National Institutes of Health vaccine trial Australian consortium

♦ Professor Chris Burrell and Dr Li Peng’s continuing contributions to knowledge about early events in HIV replication

♦ the sustained role played by Associate Professor Nick Deacon and several of his Centre colleagues in molecular analysis of the Sydney Blood Bank cohort of non-progressors.

The Panel noted the assessors’ concern that the basic research program lacked cohesion. This was reflected in the use of such terms as ‘The performance of this team in providing a concerted and multifaceted approach to specific scientific questions was not readily apparent’; ‘Each aim tended to reflect aspects of the relevant [principal investigator’s] personal research program, rather than to reflect an integrated and cohesive and matrix research initiative’; ‘The material provided indicates that collaborations within the National Centre in HIV Virology Research have not been developed to a high level’; and ‘A possibly disconcerting pattern of overlap in both previous research activities and future plans was apparent’. The outcome of these comments was that the Program Grant application to the NHMRC was unsuccessful.

The Director’s response to the assessors’ comments went some way to allaying these concerns, particularly in relation to the suggestions of redundancy of certain elements of the work plan. After 2003 the issue will only be relevant with respect to any future Program Grant applications that may emanate from current Centre staff. The Panel suggests that members of the eight HIV-related nodes that make up the existing Centre consider alternative groupings, which could well incorporate principal investigators from other organisations.

The Panel’s attention was drawn to the confusion surrounding submission of Project Grants to the NHMRC, which had resulted in some applications in the 2001 round being incorrectly classified ineligible. With one exception, this matter has now been resolved, and Centre staff submitted a number of project grants in parallel with the Program Grant application this year. The exception concerns a project from the Vadas–Lopez laboratory that does not fall within the strategy research ambit. This project, although deemed to be of high scientific merit by the Panel, remains ineligible for NHMRC funding since the principal investigators currently...
hold a Program Grant awarded under the previous scheme. The Panel recommends that this impediment to access to competitive funding be removed.

In the past the Centre was successful in attracting very substantial industry support through the now defunct Research and Development syndication scheme for development of a live attenuated HIV vaccine based on the Sydney Blood Bank cohort virus. Overseas funds were also obtained from the International AIDS Vaccine Initiative, for DNA vector work; the Fogarty Foundation, for investigating the relationship between malaria and HIV transmission from mother to child in Malawi; and a National Institutes of Health grant for hepatitis C virology. Most recently, Professor Crowe and her colleagues have been awarded a prestigious National Institutes of Health grant for their work in collaboration with overseas centres (see Section 5.4.4). Overall, the Panel considered that these successes represent a very creditable effort in what is a highly competitive marketplace.

Productivity, as measured in terms of publications, has been creditable: 126 papers have been published during the current quinquennium, including a steady flow in high-impact specialist journals such as Nature Immunology, the Journal of Virology, the Journal of Immunology, AIDS and the Journal of Infectious Disease. These publications encompassed both non-strategy and strategy research. The Panel did not concur with the suggestion of one assessor of the Program Grant that productivity ‘is on a gentle downward trend’. Rather, it has been maintained at a very good, albeit not outstanding, level.

5.4.3 Strategy scientific achievements

The Centre’s submission to the review contained significant detail on its strategy research–related achievements, which effectively encompassed the relevant services specified in its Terms of Reference (points 2, 3 and 6). Attention is drawn in particular to:

♦ molecular epidemiology—including subtype and linkage analyses, sequencing of isolates, and HIV resistance genotyping

♦ immunovirology—for example, neutralising antibody assays (with the National Centre in HIV Epidemiology and Clinical Research and the National Serology Reference Laboratory)

♦ support for HIV vaccine development

♦ anti-retroviral susceptibility testing—for example, in HAART recipients (with the National Centre in HIV Epidemiology and Clinical Research)

♦ seminal transmission analysis

♦ technology transfer to Asia–Pacific and African countries.

Provision of these services was a team effort between nodes and between the National Centre in HIV Virology Research and the National Centre in HIV Epidemiology and Clinical Research, involving several senior investigators. The Panel notes the valuable contributions made by McPhee, Crowe, Ramshaw, Burrell, Deacon and Harrich, and it considers that the Centre has fulfilled its obligations well here, except with respect to the National Institutes of
Health vaccine trial (see below) and clinically oriented studies conducted outside the Centre and requiring immunovirology monitoring.

Following the 1997 review, Dr Stephen Kent left the Centre, apparently because of a lack of funding, which meant that the Centre was deprived of ready access to the subhuman primate facility he manages. As a consequence, the only direct link into the National Institutes of Health HIV vaccine initiative has been restricted to Professor Ian Ramshaw’s laboratory, and makeshift arrangements had to be made to ensure adequate immunovirological support for the initiative. The Panel recommends that Dr Kent’s relinking to the Centre be a priority for the future.

5.4.4 Research dissemination and exchange

Training

The Centre, in conjunction with the Burnet Institute, has a very commendable track record, both in the training of graduate students and in establishing postdoctoral research fellows on career paths in HIV/AIDS. Thus it has fulfilled one of the most important Terms of Reference specified by ANCAHRD. In the future it will be vital for this process to continue if the National HIV/AIDS Strategy is to remain on track.

Service of Centre staff

Senior staff have contributed on a regular basis to the activities of various national committees, international agencies (such as the WHO and UNAIDS) and training programs. The Centre has also been involved in the organisation of national meetings and workshops that collectively have not only maintained its profile but have also contributed to the effectiveness of ANCAHRD’s activities in Australia and the region.

Collaborations

As noted, collaboration between nodes within the Centre and between the Centre and the other National Centres has been short of optimal. On the other hand, the Panel acknowledges that the situation is improving, that joint publications (12 in the current quinquennium) do not necessarily give an accurate estimate of the real extent of collaboration, and that interaction has been limited by the constraints imposed by the recent changes in funding mechanisms. Innovative groupings within the new NHMRC Program Grant scheme have the potential to foster transdisciplinary collaboration in the future.

The Scientific Advisory Committee

The Panel acknowledges the Scientific Advisory Committee’s long-standing contributions to the running of the Centre. Professors Shellam, Moss and Canavan attended the interview and participated in discussions, which was most helpful. On the other hand, the Panel was informed that the Scientific Advisory Committee had not met as frequently as it should have during the current quinquennium.

The Scientific Advisory Committee’s Terms of Reference were deemed appropriate by the Panel. It would, however, be sensible to review the role of this Committee if the structure of
the Centre were to be revised in the future, particularly with respect to the Committee’s input in budgetary and administrative matters, since funding is currently determined by the Population Health Division and the University of Melbourne is the administrating body. Moreover, a brief written report prepared annually for circulation to relevant parties would be most desirable, so that there is a formal record of the Committee’s deliberations.

5.4.5 Conclusions

The Centre represents a major asset in the medical science scene in Australia. It will therefore be important to preserve the technical capacity the Centre embodies when future structures are under consideration. The Panel recommends that the Centre and its multi-site structure be maintained. In doing so, the Panel notes the strong support for such a recommendation from the great majority of stakeholders. The Panel considers, however, that the Centre’s activities should be restricted to HIV/AIDS and that a separate system should be developed to meet the needs of the National Hepatitis C Strategy.
5.5 FUTURE DIRECTIONS

5.5.1 Preamble

The Panel’s comments on future directions are predicated on the following assumptions:

♦ The Centre will continue in its current form, at least until the end of 2003.

♦ The transfer of current staff’s non-strategy research to the NHMRC will largely be completed by the end of 2003.

♦ A national centre with a nodal structure is essential in the future to underpin the National HIV/AIDS Strategy.

♦ Funding for such a centre after 2003 will be directed to supporting core strategy research activities (as specified in the current Terms of Reference) whereas basic research will be funded through the NHMRC.

Reference is made in Section 5.4 to Program Grant funding for non-strategy research that could be done by Centre staff in conjunction with colleagues from other organisations. With respect to strategy research, the requirements can be divided into short term (the next 18 months) and longer term.

5.5.2 Short-term plans

An interim Director

Given that Professor Mills has announced his resignation from the directorship of the Centre as well as the Burnet Institute, an urgent priority is to seek an interim Director whose primary tasks will be to oversee National Centre in HIV Virology Research activities and to mentor existing staff as they transfer to the NHMRC between the departure of the incumbent Director and the end of 2003. In the Panel’s opinion, a senior member of the current Centre would be the most suitable choice, but that member need not be located in one of the Melbourne nodes. His or her responsibilities should be enunciated precisely, to ensure clarity for the various stakeholders, particularly the scientific staff. Regardless of who is chosen, it would make good sense to continue with the existing administrative arrangements.

The Scientific Advisory Committee will have a crucial role to play in providing advice to the interim Director and written reports through that person to ANCAHRD (via the Clinical Trials and Research Committee) and the NHMRC. This should include exploring new strategic relationships with colleagues outside the Centre as a means of developing alternative groupings for Program Grant applications.

The Panel had the opportunity to interview Professor Steve Wesselingh, incoming Director of the Burnet Institute, and was favourably impressed with his grasp of the situation and his willingness to cooperate during the interim period, until the end of 2003.
Strategy research program

During the next 18 months it will be important for the Centre to have the ability to continue providing the services outlined in points 2, 3 and 6 of its Terms of Reference and to make some adjustments based on the comments and suggestions outlined in the earlier sections of this report. In particular, the Panel considers it will be important, for the sake of both the research staff and the National HIV/AIDS Strategy, to:

- work vigorously on the interface with the National Centre in HIV Epidemiology and Clinical Research
- strengthen the links with the National Institutes of Health vaccine trial consortium
- improve the immunovirology support for clinical studies
- establish a formal link with the subhuman primate facility managed by Dr Kent.

Budget

Adequate funding should be provided by the Population Health Division in 2003 (and if necessary part of 2004) to maintain the strategy research activities of the Centre and to support existing staff during their transition to the NHMRC. The Panel notes the budget requested in the quinquennial review submission:

- $1 080 000 for the eight nodes
- $291 673 representing ‘glue’ funding.

The former amount is reasonable and will facilitate the smooth transition of Centre staff to the NHMRC. The latter figure includes an allocation for the salaries of the Director and Deputy Director, plus essential administrative support. If the Population Health Division and ANCAHRD approve the appointment of an interim Director, this figure will need to be revised. When doing so, it is suggested that the Scientific Advisory Committee be consulted about the specific allocations to individual nodes.

5.5.3 Longer term plans

A remodelled Centre

The Panel developed the view that the time is ripe for remodelling the Centre. The two essential elements of such a proposal are:

- to keep hepatitis C strategy research separate from the Centre for the reasons given previously
- to seek expressions of interest from consortiums of scientists around the country with expertise in HIV virology and immunology.

The second element is not intended as an indictment of either the existing Centre or its senior staff. Rather, it is seen as offering them (and other groups) the opportunity to build on past
experience, to develop new interactions, and to put forward an innovative proposal that can meet the new challenges posed by management of HIV/AIDS in this country. If approved, the appointment of a new Director would need to follow the tendering process.

The Panel recommends as follows:

♦ that a remodelled Centre retain a nodal structure

♦ that the remodelled Centre’s headquarters need not be located at the Burnet Institute and that it need not be managed by the University of Melbourne

♦ that the remodelled Centre be designed to provide core expertise needed for essential strategy services, with non-strategy research being funded by the NHMRC

♦ that the remodelled Centre incorporate greater depth in immunology, with a view to providing adequate immunovirology support for clinical studies and collaborations with the National Centre in HIV Epidemiology and Clinical Research.

Strategy research priorities

The strategy research program should continue to comply with the objectives of the National HIV/AIDS Strategy, including items 3.4.1, 3.4.5, and 3.5. Given a nodal structure, this is clearly feasible. The Terms of Reference should incorporate the following:

♦ providing the molecular component of epidemiology, including subtype analysis, linkage studies and sequencing of isolates—further examples are well summarised in the submission to the quinquennial review

♦ acting as the Australian repository of research reagents and providing specialised facilities for HIV research projects

♦ maintaining and creating links with HIV/AIDS programs in developing countries, particularly in the Asia–Pacific region

♦ providing expertise for immunovirological monitoring of patients (including sero-epidemiology) and cohort studies

♦ drug resistance phenotyping

♦ capability for supporting development of vaccines and biological response modifiers

♦ fostering a relationship with the National Serology Reference Laboratory on quality assurance.

In emphasising strategy research objectives, the Panel acknowledges that it can be difficult to separate service-related research from basic research being conducted within the nodes of a national centre. This difficulty can be resolved by ensuring that the Centre provides a work plan for each year that would require approval from the funding authority on the recommendation of the Scientific Advisory Committee.
With respect to the value of this type of research activity, it should be stressed that it represents a classic example of translational research endorsed in the Wills report, provides viable links to industry, and is a conduit for promoting collaborative work.

**Funding**

Separation of strategy and non-strategy research has obvious implications for funding and management of the National Centres. The Panel considers that creation of a remodelled National Centre in HIV Virology Research should be accompanied by a review of funding and management procedures. In particular, the role of the NHMRC and the Australian Research Council as potential funders and managers should be investigated and a mechanism assured of securing a substantial component of infrastructure funding if a university retains any managerial role.
5.6 APPENDIX A  THE REVIEW PANEL’S TERMS OF REFERENCE

Following are the Terms of Reference for the Review Panel:

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

♦ The current strategic planning processes, goals and priorities and progress made towards meeting the stated goals/priorities;

♦ 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;

♦ The extent to which the goals and activities reflect the needs of key stakeholders (ie Commonwealth and State/Territory policy makers, ANCAHRD, AFAO (Australian Federation of AIDS Organisations), Hepatitis C organisations, NAPWA (National Association of People Living With HIV/AIDS), the medical and research communities (including ASHM (Australasian Society for HIV Medicine)), and Aboriginal people and Torres Strait Islanders);

♦ 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;

♦ 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

♦ The nature, appropriateness and effectiveness of Centre mechanisms for disseminating research findings and information policy developments.

♦ The extent and value of the collaboration of the Centres with researchers in the HIV/AIDS, hepatitis C and related areas (eg Drug and Alcohol Research Centres) and the Centres’ success in encouraging leading researchers to focus attention on HIV, hepatitis C and related research.

♦ 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, WHO and overseas universities/research centres.

♦ 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; and
– the capacity of existing Centres to attract and maintain external funding.

♦ 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

♦ Other matters considered relevant or which emerge during the review.
5.7 APPENDIX B THE CENTRE’S TERMS OF REFERENCE

Following are the Terms of Reference for the National Centre in HIV Virology Research:

1. To conduct research on the basic virology, pathogenesis and immunology of HIV and related immunodeficiency retroviruses in order to increase our understanding of the disease processes and to assist in the development of new diagnostic and monitoring strategies, new treatment modalities and new methods for blocking transmission of, and infection with, these viruses.

2. To develop collaborative research internationally, particularly in the Asia-Pacific region.

3. To act as an Australian repository for research reagents for the HIV/AIDS fundamental research effort, and to make those reagents available to Australian scientists conducting such research. To link with overseas HIV/AIDS and other research reagent programs, to facilitate the access of Australian investigators to those reagents and to make Australian reagents available to overseas colleagues.

4. To provide specialised, scarce or expensive research facilities which are required for HIV/AIDS research and to make those facilities available to other investigators as appropriate.

5. To collaborate with the National Centre in HIV Epidemiology and Clinical Research and other groups and individual researchers as appropriate in the clinical studies of the biology, natural history, pathogenesis, treatment and prevention of HIV infection.

6. To provide tangible opportunities and encouragement for postgraduate and postdoctoral training of scientific and medical staff in all aspects of retrovirology.

7. To disseminate the results of the Centre’s research through all possible means, including presentations at national and international meetings, publications, through the media, and in an annual report.

8. To perform other roles in the study of HIV/AIDS infection and retrovirology which may be determined from time to time by the Director, in consultation with the ANCAHRD Research Advisory Committee and approved by the Department of Health and Family Services.
2002 QUINQUENNAL REVIEW OF THE NATIONAL CENTRE IN HIV SOCIAL RESEARCH AND THE AUSTRALIAN RESEARCH CENTRE IN SEX, HEALTH AND SOCIETY

Professor Peter Aggleton
Professor Lois Bryson
Associate Professor Phyllis Butow
6.1 SUMMARY AND RECOMMENDATIONS

6.1.1 Summary

In the five years since the last review, the National Centre in HIV Social Research and its collaborating Centre, the Australian Research Centre in Sex, Health and Society, have continued to do social research of the highest international standard.

Having reviewed a wide range of evidence from a number of sources, including submissions from both Centres, interested stakeholders, and an independent academic assessor, the Review Panel is of the opinion that the work of the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society is of the highest quality by international standards. The mix of work is intellectually rigorous and has led to the development of theoretical insight that has continuing relevance for policy and practice, both in Australia and elsewhere.

Current work combines theoretical rigour and engagement with a wide range of bodies responsible for developing HIV/AIDS policy and practice interventions. Both Centres have a record of working responsively with the communities that are most affected. This result would not have been possible without continued investment by government and the commitment and professionalism of the individuals working in each Centre. Sustained investment has paid off.

The importance of social research

It is important to recognise the significant contribution that social research has made to Australia’s highly regarded partnership response to HIV/AIDS. Twenty years of international experience of the epidemic continue to demonstrate the value of this approach and the importance of social research as a vital component of a successful response. Social research is essential to explaining why and how patterns emerge within the epidemic. Importantly, and in addition, social research helps pinpoint the most effective areas of intervention and provides the best means of monitoring and evaluating interventions.

Research priorities for the next phase

The Review Panel considers that there are six key areas of endeavour in the field of social research that will continue to be fundamental to Australia’s nationally coordinated response to HIV/AIDS, hepatitis C and the sexual health of Indigenous Australians. These areas are:

♦ understanding changing sexual and drug-related practices in especially vulnerable population groups, including gay and other homosexually active men, people who inject drugs, people in custodial settings, people living with HIV/AIDS and hepatitis C, sex workers, and people from non–English speaking backgrounds

♦ continuing studies of specific sexual and drug-related practices, subcultures and contexts

♦ work on prevention, response and sexual health in Indigenous communities

♦ studies of the role and effectiveness of education in programs targeting prevention
♦ studies of the changing life experiences of people living with, and affected by, HIV/AIDS and hepatitis C, and the contribution of these people to Australia’s response to the epidemic

♦ studies in areas where gaps in knowledge exist—for example, the history, economics, and politics of the epidemic and documentation and analysis of the Australian response.

### 6.1.2 Recommendations

The following is recommended:

135. The Panel considers that the future social research program at both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society would benefit from more formalised planning in a number of areas:

- in relation to funding sources and conditions, the identification of priority fields for research and the need to achieve a balance between research in HIV/AIDS, hepatitis C and sexual health in both the Indigenous and general populations

- clearer demarcation of research effort between the two Centres in relation to their respective strategic strengths and track records in the production of high-quality research

- processes for undertaking international work in a coordinated fashion.

136. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society continue to build on their respective research strengths, both substantively and methodologically, in a complementary and collaborative fashion.

137. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage exploration of joint activities such as publications, conferences and seminars, senior researcher training and development, new forms of community liaison, and induction for new research staff.

138. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage fuller involvement of their senior researchers in joint planning processes.

139. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society prepare explicit statements dealing with joint agreements between the two Centres and ensure the dissemination of these statements.

140. That, with a view to promoting research-career development, the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage the introduction of a rolling program of career and professional development for staff at all levels in both organisations. Such a program could include emphasis on the provision of support and mentoring for publication and the development of a staff exchange program within and between the various components of the HIV/AIDS social research programs, at these Centres and elsewhere.
141. That existing mechanisms for accountability and scientific direction, including the Scientific Advisory Committees, be retained. Efforts should be made to encourage joint planning with respect to the development of research programs, inclusive of the respective Scientific Advisory Committees of both the Centres.

142. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society develop systematic policies for striking the best balance in relation to publication of research results—including consideration of formalising systems for encouragement and support for publishing and setting annual targets for staff at different levels in each Centre.

143. That the host institutions for both Centres give consideration to the creation of a greater number of stable research positions.

144. The Panel recognises that liaison with government is a two-way process, but pursuit of a clearer and more coherent relationship with AusAID would be a distinct advantage to both Centres. Beyond this, and to further augment the two Centres’ capacity to work outside Australia, development of stronger relationships with UN agencies should become a priority.
6.2 THE REVIEW PROCESS

The members of the Review Panel were:

Chair: Professor Peter Aggleton  
Thomas Coram Research Institute  
Institute of Education  
University of London

Members: Professor Lois Bryson  
Department of Social Science and Planning  
RMIT University

Associate Professor Phyllis Butow  
Medical Psychology Research Unit  
University of Sydney

Secretariat support was provided by Mr Paul Lehmann, Commonwealth Department of Health and Ageing.

The Terms of Reference for the review are set out in Section 6.5 (Appendix A).

Both Centres were required to present a written submission to the Review Panel in April 2002, in the format of an NHMRC Program Grant, detailing projects, achievements and future plans.

Three independent experts were asked to assess and rate the achievements, research plan and team, and cooperation based on the Centres’ submissions. Only one such assessment was received before the date of the review. The Centres were subsequently given the opportunity to reply to that assessor’s report.

Submissions were sought from stakeholders and interested parties. Written submissions were received from:

♦ the Victorian Department of Human Services
♦ the New South Wales Department of Health
♦ the Australian Federation of AIDS Organisations
♦ the Australian Hepatitis Council
♦ the University of New South Wales
♦ the Australian Liver Association of the Gastroenterological Society of Australia
♦ the National Association of People Living with HIV/AIDS
♦ the Australasian Society for HIV Medicine
♦ the Australian Injecting and Illicit Drug Users League
The Review Panel met with the Director and Deputy Director of the National Centre in HIV Social Research and the Director of Australian Research Centre in Sex, Health and Society on Monday 2 June 2002. This was followed by a site visit at Australian Research Centre in Sex, Health and Society, in Melbourne. The Review Panel continued its deliberations on Tuesday 3 June 2002, meeting with Director of the National Centre in HIV Social Research at the University of New South Wales for a site visit.

An oral report of the Panel’s findings and provisional recommendations was presented by the Chair, Professor Peter Aggleton, to the Strategy Research Review Team on 4 June 2002. The draft report containing the Panel’s recommendations was submitted by the Chair on the same day.
6.3 BACKGROUND

The National Centre in HIV Social Research was first established in 1990. Following a public tender, competing bids from the University of Queensland, the University of New South Wales and Macquarie University were combined to establish a three-site Centre, under the directorship of Professor Beverley Raphael at the University of Queensland.

The Centre was reviewed in 1992. The review recommended the closure of the University of New South Wales unit and made a number of other recommendations concerning the management and direction of the remaining two-site Centre.

The post-review arrangements did not work satisfactorily and there were unproductive tensions between the two units. Professor Raphael announced her intention to resign from the directorship in mid-1994, and at the beginning of that year the then Minister for Health asked a committee to make recommendations concerning future administrative arrangements for the Centre. The committee comprised of Professor Peter Karmel, Dr Claire Parsons and Professor Ann Daniel, who had chaired the 1992 review.

The Karmel committee considered three possibilities for future administrative structures:

- two or more operating units with a director at one unit
- a single national centre at one location
- a number of independent operating units.

In the light of the Centre’s history, the Karmel committee proposed that social research in HIV be fostered by a number of independent programs, with the task of facilitating social research nationally being assigned to a member of the Commonwealth AIDS Research Grants Committee.

Accordingly, three priority programs were established: a program on gay and homosexually active men, at Macquarie University; a program on youth and the general population, at the Centre for the Study of Sexually Transmissible Diseases at La Trobe University; and a program on people living with HIV/AIDS and their carers, at the School of Nursing at La Trobe University. In September 1996, this third program was transferred to the Centre for the Study of Sexually Transmissible Diseases under Professor Doreen Rosenthal.

The Commonwealth’s HIV/AIDS social research program was again reviewed in 1997. In addition to recommending that the National Centre in HIV Social Research based at Macquarie University be moved to the University of New South Wales, the Review Panel recommended that funding be continued for a further five years. Responsibility for developing annual programs of research for both the National Centre in HIV Social Research and the program based at La Trobe was given to reconstituted Scientific Advisory Committees. Also following the 1997 review process, the Centre for the Study of Sexually Transmissible Diseases at La Trobe University was designated a collaborating centre to the National Centre in HIV Social Research.

In 1998 the Centre for the Study of Sexually Transmissible Diseases changed its name to the Australian Research Centre in Sex, Health and Society. The National Centre in HIV Social Research completed its move to the University of New South Wales in January 1999.
6.4 COMMENTS AGAINST THE REVIEW PANEL’S TERMS OF REFERENCE

6.4.1 Research goals and priorities

Term of reference

The Review Panel was required to review and make recommendations on ‘the current strategic planning processes, goals and priorities and progress made towards meeting the stated goals/priorities’.

Comment

Planning processes have been effective in following the National HIV/AIDS Strategy and, where relevant, the National Hepatitis C Strategy and the National Indigenous Australians’ Sexual Health Strategy, each of which guides the work of the two Centres. As the Centres have matured they have also been successful in achieving a balance in responding to emerging issues at national, local and discipline levels.

Recommendation 135

The Panel considers that the future social research program at both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society would benefit from more formalised planning in a number of areas:

♦ in relation to funding sources and conditions, the identification of priority fields for research and the need to achieve a balance between research in HIV/AIDS, hepatitis C, and sexual health in both the Indigenous and general populations

♦ clearer demarcation of research effort between the two Centres in relation to their respective strategic strengths and track records in the production of high-quality research

♦ processes for undertaking international work in a coordinated fashion.

Term of reference

The Review Panel was required to review and make recommendations on ‘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’.

Comment

The Panel is of the view that the different, but related, research perspectives and approaches of each Centre inform the current research programs of both Centres. In discussing these different approaches, the Panel noted the different research emphasis of the National Centre in HIV Social Research (theoretical aspects of sexual practice and its contextuality) and
Australian Research Centre in Sex, Health and Society (a focus on HIV in the broader context of sexual health).

The Panel considers that the complementary nature of these approaches is additive and likely to promote a suitable depth of engagement with aspects of social research relevant to the epidemics.

The perspectives brought by the two Centres have validity in the current research context and are producing valuable individual contributions. These complementary approaches enhance the capacity of social research in Australia to detect and effectively respond to emerging priorities.

**Recommendation 136**

That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society continue to build on their respective research strengths, both substantively and methodologically, in a complementary and collaborative fashion.

**Term of reference**

The Review Panel was required to review and make recommendations on ‘the extent to which the goals and activities reflect the needs of key stakeholders (ie the Commonwealth and State/Territory policy makers, ANCAHRD, Australian Federation of AIDS Organisations, hepatitis C virus organisations, National Association of People Living with HIV/AIDS, the medical and research communities (including the Australasian Society in HIV Medicine)), and Aboriginal people and Torres Strait Islanders’.

**Comment**

The Panel took account of the views of a wide range of stakeholders (see Section 6.2). The view of the overwhelming majority of these stakeholders was very positive, and a clear majority appreciated the contribution and flexibility of the Centres in meeting stakeholders’ needs. The criticisms that were expressed came from a minority of submitters and, on the whole, were not related to the quality of the academic output.

The Panel recognises that calls for a nationally coordinated response to hepatitis C and sexual health have resulted in the Centres doing some limited work in these areas, within the constraints of existing funding. The Panel supports continued efforts to forge links with affected groups in the areas of hepatitis C and sexual health, including Indigenous Australians’ sexual health. The Centres have much to offer in terms of expertise and experience and, subject to resourcing, the capacity to take on additional work.

The Panel questioned the need to establish a radically new structure for social research related to hepatitis C. However, the issue of appropriate and adequate funding for hepatitis C social research must be resolved before substantial good-quality work can be done in this field without detriment to HIV/AIDS social research.
**Term of reference**

The Review Panel was required to review and make recommendations on ‘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’.

**Comment**

The current National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society management and liaison structures have developed over time and have served the Centres well thus far. Looking to the future, however, and in order to consolidate recent achievements, the Panel considers the Centres should give more consideration to:

- taking greater advantage of the considerable skills and experience of senior researchers through professional development of senior staff
- ensuring that the work of each Centre is disseminated as appropriately and widely as possible
- capitalising on the benefits of the different approaches the two Centres bring to social research in HIV/AIDS, hepatitis C and sexual health.

While recognising the value of general sexual health research and acknowledging the directions set by funding sources, the Panel is concerned that the imminent departure of Australian Research Centre in Sex, Health and Society’s Deputy Director for at least two years may pose a challenge to that Centre’s continuing direct contribution to Australia’s response to HIV/AIDS.

**Recommendation 137**

That the National Centre in HIV Social Research Australian Research Centre in Sex, Health and Society encourage exploration of joint activities such as publications, conferences and seminars, senior researcher training and development, new forms of community liaison, and induction for new research staff.

**Recommendation 138**

That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage fuller involvement of their senior researchers in joint planning processes.

**Recommendation 139**

That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society prepare explicit statements dealing with joint agreements between the two Centres and ensure the dissemination of these statements.
Recommendation 140

That, with a view to promoting research-career development, the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage the introduction of a rolling program of career and professional development for staff at all levels in both organisations. Such a program could include emphasis on the provision of support and mentoring for publication and the development of a staff exchange program within and between the various components of the HIV/AIDS social research programs, at these Centres and elsewhere.

Term of reference

The Review Panel was required to review and make recommendations on ‘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’.

Comment

Although this matter was not explored in depth, the Panel is satisfied that existing processes for evaluation, scientific guidance and accountability with respect to research objectives are functioning satisfactorily and in a manner that lends support to the production of high-quality research.

The Panel notes that the membership of the Scientific Advisory Committees for both the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society is reflective of each Centre’s inclusive and responsive approach to the research it does.

Recommendation 141

That existing mechanisms for accountability and scientific direction, including the Scientific Advisory Committees, be retained. Efforts should be made to encourage joint planning with respect to the development of research programs, inclusive of the respective Scientific Advisory Committees of both the Centres.

6.4.2 Research dissemination and exchange

Term of reference

The Review Panel was required to review and make recommendations on ‘the nature, appropriateness and effectiveness of Centre mechanisms for disseminating findings and information policy developments’.
Comment

The ability to rapidly disseminate research results—via the Internet and in other ways—is a particular strength of both Centres. In addition, the Panel praised both Centres for their ability to package and pitch research results in such a way as to maximise the results’ relevance and usefulness for different target audiences, including affected communities.

The Panel is of the view, however, that more consideration should be given to the balance between publication of material relevant to policy and practice and more traditional academic publication. In particular, the Panel feels that, in some instances, additional emphasis on increasing the number and range of publications arising from Commonwealth-funded research, in peer-reviewed academic journals, is warranted. In reaching this conclusion, the Panel notes the respective publication records of the Centres and acknowledges that the nature and extent of the academic publication balance is an issue of which both Centres are cognisant.

The Panel considers that the establishment of a suitable balance of publication in peer-reviewed journals and other forms of research dissemination is important for a number of reasons, including:

♦ promoting greater international recognition of the high quality of Australian HIV/AIDS social research

♦ enhancing the capacity of both Centres to obtain funding

♦ assisting the development of career paths among senior researchers.

Recommendation 142

That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society develop systematic policies for striking the best balance in relation to publication of research results—including consideration of formalising systems for encouragement and support for publishing and setting annual targets for staff at different levels in each Centre.

Term of reference

The Review Panel was required to review and make recommendations on ‘the extent and value of the collaboration of the centres with researchers in the HIV/AIDS, hepatitis C virus and related areas (eg Drug and Alcohol Research Centres) and the centres’ success in encouraging leading researchers to focus attention on HIV, hepatitis C virus and related research’ and ‘the value of the centres’ relationships/collaborative arrangements with other key organisations, such as

♦ centres funded under the Public Health Education and Research Program:

♦ funding bodies;

♦ government departments;
Comment

Both Centres’ submissions to the Panel provided ample evidence of a wide range of collaborative efforts between the Centres and other researchers in HIV/AIDS, hepatitis C and related areas. Contrary to the views expressed by a very small minority of stakeholders, the Panel found that the Centres were engaged in an impressive range of interactions and collaborations with external researchers, and more broadly, with communities and other stakeholders. The Panel considers that, while there is always room to improve in this area, with the maturing of the Centres over the five years since the last quinquennial review, significant progress had been made toward the goal of promoting inter-centre collaboration.

In addition to encouraging a national focus on social research through their many collaborative efforts, the Centres’ success in encouraging researchers in the field is further attested to by their capacity to attract postdoctoral social researchers and other multidisciplinary researchers.

The Panel found, almost without exception, that both the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society were highly regarded by the organisations with which they interacted. Very good working relationships were evident between the two Centres and their respective funding bodies and between the Centres and those communities most affected by HIV/AIDS. Importantly, the Panel found that both Centres have very good relationships with their host institutions. They both enjoy a high standard of physical accommodation and supportive academic and administrative arrangements from their respective faculties.

In discussing the question of relationships between the Centres and their respective host institutions, the Panel turned to consideration of possible future support for the Centres. In particular, the Panel sees a need to think more creatively about ways of working with university administrations in order to optimise staff-development opportunities within and between the two Centres.

For example, consideration could be given to the creation of a limited number of two- to three-year rolling contracts for researchers, offered subject to the availability research funds. The University of London has established such a mechanism for research staff at the Thomas Coram Research Unit, whose funding circumstances are quite similar to those of the Centres. An arrangement of this kind would provide staff with a greater sense of security, increase the attractiveness of the Centres as an employer of choice, and improve the capacity for longer term planning. At the same time, an arrangement of this nature would not ordinarily involve additional costs to the host university, except in circumstances where the associated funding stream unexpectedly diminishes. Even then, this would involve relatively small amounts of funding, since in such cases planning for redundancy would need to factored into the process of managing the rolling contract arrangement.

Recommendation 143

That the host institutions for both Centres give consideration to the creation of a greater number of stable research positions.
Term of reference

The Review Panel was required to review and make recommendations on ‘the extent and value of additional funding attracted by the National Centres including:

- the extent to which this funding contributes to the Centres’ primary goals;
- the value to Australia of such external funding; and
- the capacity of existing centres to attract and maintain external funding’.

Comment

In reviewing the submissions from both Centres, the Panel found clear evidence that a range of Australian funding bodies now support research done within the Centres. For both the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society, the quantum of these additional research funds has increased significantly over time. Funding sources beyond the core Department of Health and Ageing grant now include state health departments, the Australian Research Council, and the NHMRC.

The Panel is of the view that the Centres’ ability to augment and diversify their respective funding streams is largely a result of the relatively stable funding base. In the case of Australian Research Centre in Sex, Health and Society, this has enabled a broadening of work in the field of sexual health; in the case of the National Centre in HIV Social Research, it has added greater depth to its HIV/AIDS research program. In each case, additional funding has enabled primary goals to be more coherently addressed, strengthening the Centres’ capacity to contribute to Australia’s social response to HIV/AIDS.

Nevertheless, the Panel considers it important that both Centres remain vigilant in continuing to strike an appropriate balance between the core funded research program and other research they may be called on to do from time to time.

Term of reference

The Review Panel was required to review and make recommendations on ‘the extent and value of the training opportunities provided by the Centres for researchers and those working in areas relevant to the Centres’ activities’.

Comment

The Panel considered the submissions from both Centres and commended the Centres on the wide range of training opportunities provided, including training for researchers and others from outside the Centres.

While not seeking to make extensive comment against this point of the Terms of Reference, the Panel draws attention to other recommendations in this report that cover staff development and training.
Term of reference

The Review Panel was required to review and make recommendations on ‘other matters considered relevant or which emerge during the Review’.

Comment

Despite the Centres’ excellent record to date, the Panel considers that the work of both Centres would benefit from further strengthening of communication of the importance of social research to government, funding bodies and the broader community. In this respect, the Centres may wish to consider pursuing a focus on the value of social research in the evaluation of education and prevention programs.

Promoting the importance of social research for Commonwealth-funded interventions as a means of enhancing research programs would also strengthen support for an evidenced-based approach to program development and implementation.

Further, promotion of the role and importance of social research may also help to develop consensus on some of the diverse interests associated with social research, especially in newer social research fields such as hepatitis C and Indigenous Australians’ sexual health. It may also foster close interaction with social researchers outside the Centre structure and encourage growth in the quantity and quality of social research done outside the Centres and in other parts of Australia.

The Panel considers that both Centres are now exceedingly well placed to expand the nature of their HIV/AIDS work to incorporate international issues. Building social research capacity in other countries through cooperative intellectual, policy and practice interchange should be a focus for the Centres’ HIV/AIDS work.

As part of the process of developing their international strategy, and in order to undertake research relevant to the broader international context, the Centres may wish to consider targeting selected international funding bodies, including some of the better known charitable and philanthropic organisations, in a more systematic fashion.

The National Centre in HIV Social Research was last reviewed in 1997, and the reviewers made 14 recommendations (see Section 6.7 (Appendix C)). This current Review Panel noted key achievements against these recommendations during its deliberations, including the transferral of the National Centre in HIV Social Research from Macquarie University to the University of New South Wales.

Recommendation 144

The Panel recognises that liaison with government is a two-way process, but pursuit of a clearer and more coherent relationship with AusAID would be a distinct advantage to both Centres. Beyond this, and to further augment the two Centres’ capacity to work outside Australia, development of stronger relationships with United Nations agencies should become a priority.
6.5 APPENDIX A  THE REVIEW PANEL’S TERMS OF REFERENCE

Following are the Terms of Reference for the Review Panel:

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

♦ The current strategic planning processes, goals and priorities and progress made towards meeting the stated goals/priorities;

♦ 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;

♦ The extent to which the goals and activities reflect the needs of key stakeholders (ie Commonwealth and State/Territory policy makers, ANCAHRD, AFAO, Hepatitis C organisations, NAPWA, the medical and research communities (including ASHM), and Aboriginal people and Torres Strait Islanders);

♦ 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;

♦ 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.

♦ Evaluate the cost-effectiveness, utility and efficiency of hepatitis C and sexually transmissible infections (STI) surveillance as carried out by the NCHECR.

Research dissemination and exchange

♦ The nature, appropriateness and effectiveness of Centre mechanisms for disseminating research findings and information policy developments.

♦ The extent and value of the collaboration of the Centres with researchers in the HIV/AIDS, hepatitis C and related areas (eg Drug and Alcohol Research Centres) and the Centres’ success in encouraging leading researchers to focus attention on HIV, hepatitis C and related research.

♦ 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, WHO and overseas universities/research centres.

♦ 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; and

– 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

♦ Other matters considered relevant or which emerge during the review.
6.6 APPENDIX B THE CENTRES’ TERMS OF REFERENCE

Following are the Terms of Reference for the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society:

National Centre in HIV Social Research

Research
♦ To conduct research which describes and analyses the social understandings, meanings and practices of peoples, institutions and communities in relation to HIV, sexually transmitted diseases (STDs) and other communicable diseases implicated in and related to HIV transmission with a view to increasing the understanding of these aspects.

♦ To develop collaborative research internationally, particularly in the Asia-Pacific region.

♦ To establish the research of the Centre as an active and reflexive process which acknowledges the value of co-participation of the researcher and the researched in the research activity, and draws on diverse expertise from its co-participants.

Leadership and research resources
♦ To maintain collaboration with the National Centre in HIV Epidemiology and Clinical Research, the Australian Centre for the Study of Sex, Health and Society and other collaborating centres.

♦ To inform the development and implementation of policy and practice with respect to prevention and to the management of the epidemic.

Training and education
♦ To provide tangible opportunities and encouragement for post-graduate and post-doctoral training of social science and humanities students and staff in the social aspects of HIV and related diseases.

♦ To disseminate the results of the Centre’s research through all possible means, including presentations at national and international meetings, publications, through the media, and in an annual report; and to support the dissemination of social research related to HIV/AIDS, blood-borne viruses and sexually transmissible diseases to relevant communities.

Other
♦ To perform other roles in HIV/AIDS social research which may be determined from time to time by the Director, in consultation with the ANCARD Research Advisory Committee and approved by the Department of Health and Family Services.

Australian Research Centre in Sex, Health and Society: objectives
♦ To cooperatively conduct research which complements and enhances the research program of the National Centre in HIV Social Research.

♦ To cooperatively conduct research within the Terms of Reference of the National Centre in HIV Social Research (see above).

♦ In accordance with the Conditions of Award which establish this research program, and in accordance with the Memorandum of Understanding between the Director of the NCHSR, the Director of the ARCSHS and the Department of Health and Ageing, the annual HIV/AIDS and related disease social research program at ARCSHS will be
developed in close consultation with the Director of the NCHSR, for submission to ANCARD.
6.7 APPENDIX C RECOMMENDATIONS OF THE PREVIOUS REVIEW COMMITTEE (1997)

The previous review committee made the following recommendations:

1. There should be a National Centre in HIV Social Research, funded for at least another five years.

2. There should be one geographical institutional focus for the National Centre in Sydney.

3. The Centre should make every effort to explore thoroughly, with the assistance of the Department of Health and Family Services, opportunities for re-location to the Faculty of Arts and Social Sciences at the University of New South Wales.

4. The PLWHAC (People Living With HIV/AIDS and their Carers) program should be sustained and managed, and it necessary enhanced, at the Centre for Study of STDs. Other programs such as the Youth and General Population program will continue until the end of 1998 and then be reviewed by the Advisory Committee. Future funding arrangements for National Centre projects would come through the new National Centre at University of New South Wales (UNSW). As part of this, an agreed formula for the allocation of infrastructure money should be developed between the Centre and the UNSW and any collaborating centres, including the one at La Trobe University.

5. The transition to UNSW should take place over the next eighteen months. The Director will be Sue Kippax who will hold the directorship for the following five years at which point, depending on the time line of implementing the changes, advice should be sought from the Advisory Committee.

6. The Centre should operate with a reconstituted Advisory Committee, chaired by an academic from outside the Centre, with members chosen from the research, community (including Aboriginal and injecting drug user (IDU) organisations) and government sectors. The Committee's membership should be drawn from across the country and should be chosen by the Director in consultation with the Chair of the Research Advisory Committee (RAC), the Director of the La Trobe arm, and the Department. The new Advisory Committee should be established from the beginning of 1998.

7. The Centre should develop a strategic plan to guide its operations for the next five years. This plan should encompass a research strategy which applies a conceptual framework that reflects the current and future dimensions of the research agenda. The strategy should be flexible and take into account the changing nature of the epidemic and community concerns and needs. This research strategy needs to be developed in consultation with the Advisory Committee and other national key stakeholders.

8. As part of its strategic plan, the Centre should develop a strategic approach to research dissemination. In the face of the changing epidemic and the development of technology, and advanced methods of communication, innovative dissemination strategies which complement existing strengths should be investigated, tested and evaluated. These may include the use of traditional and evolving personal networks, i.e. community development and interactive dissemination strategies that will expand the transfer of research into practice nationally.

9. As part of the development of the strategic plan, a series of consultative meetings should be held with a broad range of stakeholders in every capital city over the next eighteen months. Where possible these meetings should lead to the establishment of ongoing networks within each state.

10. The Centre should consider developing various national databases that would permit access to other researchers and collaborating centres to foster the expansion of social research in Australia and the region.
11. There should be a deputy director’s position established for the Sydney Centre, at a senior level. In order to attract a high quality field of applicants, this position should have a guarantee of continuing employment from the host university should the Centre cease operation.

12. The Centre should develop a program approach to budgeting, which aligns the allocation of resources with its strategic plan. Special one-off funding should be provided to support the consultative workshops referred to in recommendation 9 and for the additional senior staff member at the Sydney Centre. The claimed $50 000 shortfall in the Centre’s budget should be investigated by the Department.

13. Greater use should be made by the Centre of strategies for attracting researchers to work in the Centre.

14. Collaborative research between the Centre and researchers in universities and other organisational locations, and collaborations within the Asia/Pacific region, should be systematically encouraged. One-off funding should be provided to set up a series of meetings or workshops to determine appropriate roles for various individuals and organisations in the national HIV social science research effort. This process should be jointly overseen by the Centre, RAC and the NHMRC.
2002 QUINQUENNIAL REVIEW OF
THE NATIONAL CENTRE IN HIV
EPIDEMIOLOGY AND CLINICAL RESEARCH

Professor Ian VD Weller
Professor Roel A Coutinho
Dr Cathy Mead
7.1 SUMMARY AND RECOMMENDATIONS

7.1.1 Summary

In the five years since the last review, the National Centre in HIV Epidemiology and Clinical Research has continued to raise its already high national and international profile in clinical research and epidemiology. The following are among its achievements:

♦ a continuing lead role in the pathological and therapeutic aspects of primary HIV infection, with a recent award from the US National Institutes of Health of US$3.67 million over five years

♦ a pivotal role in the development of anti-retroviral therapies and their evaluation in national and multinational trial networks, substantially influencing the clinical management of HIV/AIDS in Australia and internationally. The Centre has shown international leadership in a number of areas but particularly in the movement of the investigation of the therapeutic effects of interleukin-2 from early exploratory studies to two large international phase III trials

♦ studies of the clinical, pathological and therapeutic aspects of the metabolic toxicities associated with anti-retroviral drugs

♦ the establishment of a national HIV surveillance system, which is recognised nationally and internationally as a key component of the Australian response to HIV/AIDS, and the initiation of national surveillance for hepatitis C infection

♦ studies of the risks for HIV and hepatitis C infection in Australia and modelling studies, both of which have guided the national prevention response.

In addition, the Centre is the lead site for a national consortium that was successful in gaining A$27 million from the National Institutes of Health to develop and clinically test a prophylactic HIV vaccine based on a novel approach developed in Australia.

The Centre’s publication record is also impressive. It has published nearly 600 peer-reviewed articles (some 295 in the last five years) and 212 non-peer reviewed articles. At least 130 of the 295 peer-reviewed articles in the last five years appeared in journals with an impact factor of five or greater.

Internal and external management of the Centre

Internally, a new management structure was adopted early in 2002, with an executive and six programs of research each having a program head. This structure has given greater responsibility to a group of younger, talented researchers and clarifies their roles within the Centre. But a third tier of management needs to be created, especially in the case of the Therapeutic and Vaccine Research Program, which has 21 full-time-equivalent staff.

Externally, the Centre is advised by a Scientific Advisory Committee, which is large and allows for stakeholder input as well as scientific advice. As a result, the Committee has not achieved all that the Centre staff had hoped. Additional mechanisms may need to be explored.
to expand the contribution of external expertise while not diminishing the input of stakeholders, particularly those from the community sector.

**Funding**

Since the last review, the Centre has attracted substantial funding from new sources, most notably the National Institutes of Health. The total annual award income in 1997 was A$4.77 million; it is now $11.7 million with a projected additional $20 million income from National Institutes of Health support during the next five years. However, the core funding to support surveillance and infrastructure costs has been eroded because of a lack of adjustment for inflationary costs such as staff pay awards. ‘Mainstreaming’ is not particularly relevant for a Centre whose core functions—such as surveillance and maintenance of the clinical trials network—are not funded by ‘mainstream’ research bodies. The model of funding these functions, as an integral part of the Centre, could be considered a mainstream model.

**The Therapeutic and Vaccine Research Program**

The Therapeutic and Vaccine Research Program is outstanding. It has over 30 clinical trials in progress or to be started in Australia and through the HIVNAT collaboration in Thailand. It is one of the leading clinical trial centres in the world. In the last year, 1200 patients—some 15 per cent of people known to be living with HIV infection in Australia—were in clinical trials at 40 sites. This is a remarkable achievement. The research group was among the first in the world to characterise the lipodystrophy syndrome.

The pharmacology of antiretroviral drugs is an important area of developing research. The Centre wishes to begin a program in this area but has yet to develop or identify ‘home-grown’ pharmacological expertise.

The Centre is the lead site of a national consortium that was successful in gaining A$27 million from the National Institutes of Health to develop and clinically test a prophylactic HIV vaccine.

**The HIV Epidemiology and Prevention Program**

The Centre is continuing its research into men who have sex with men, studying behavioural and biological risk factors in collaboration with the National Centre in HIV Social Research. Internationally recognised studies have been done on HIV-related cancers because of the ability to link the national HIV database with the cancer registry. This link is not available in many other countries. The future program of research will also include a phase III vaccine preparedness study in men who have sex with men and screening for a wide range of infections, a randomised controlled trial in non-occupationally HIV-exposed people, and continuation of the non-progressors cohort, which is an important resource for basic scientists to identify protective viral and host factors.

**The Viral Hepatitis Program**

The Viral Hepatitis Program includes surveillance, risk factor and long-term sequelae studies of patients infected with hepatitis B and hepatitis C. The Centre will extend its expertise in clinical trials to the assessment of treatments for blood-borne virus infection. This will be done in collaboration with the Australian Liver Association and other stakeholders through
the recently established Viral Hepatitis Working Group. There are plans to study the natural history and effects of treatment on patients with newly acquired hepatitis C infection. It is important that clinical trials in hepatitis C–infected injecting drug users be conducted in collaboration with providers of their long-term care.

**The Primary HIV Infection Program**

The Centre will continue its research in the primary infection area, for which it has already earned an international reputation and has recently been awarded funding from the National Institutes of Health of US$3.67 million over five years for a collaborative project with a group at Harvard University.

**The Biostatistics and Databases Program**

The primary role of the Biostatistics and Databases Program is to support developments across the breadth of the Centre’s work: approximately 75 per cent of the Program’s resources are dedicated to this. The Australian HIV Observational Database has been established for two years and is contributing data to large international cohort studies of the cardiovascular risks of therapy and the effects of salvage therapy. This Program illustrates the significance of a biostatistical infrastructure investment attracting additional funding in the national and international contexts.

**The Laboratory Program**

The Laboratory Program has two functions. It provides services and support for the other programs by being a repository for samples and is thus an important national resource. It is also responsible for transitional and pathogenesis research. New assays are validated and then moved into routine use. The pathogenesis research is focusing on immunological changes in primary infection, which might determine long-term outcomes such as immune escape, the effect of therapy, and novel resistance mutations. The Laboratory Program was involved in the establishment of, and now supports and audits, the laboratories in Thailand as part of the HIVNAT collaboration.

**Surveillance**

Surveillance is a core function of the Centre. Directions for future development include newly acquired infections in HIV, expansion of activities in hepatitis B and C, and development of sexually transmissible infection surveillance beyond the current passive surveillance to National STI Surveillance Strategy under the auspices of the Communicable Diseases Network Australia. The annual surveillance report is a key output. The Centre has been given a small amount of additional core funding for hepatitis B and C surveillance, but expansion into the area of STIs, with work needed to improve the quality of data, will require additional core funding.

**Role in the Asia–Pacific region**

The clinical trial effort in Thailand is now well established and the Centre has a leading role in the HIVNAT collaboration. Thailand is already involved in several vaccine trials. Setting up vaccine trials in other developing countries will require long and intensive preparation.
Support from AusAID should be sought for this important development work, and it may be necessary for the Centre to work with other groups in Australia who have a longer history of experience in developing countries.

**Indigenous Australians’ sexual health**

The Centre’s contribution to Indigenous Australians’ sexual health comes largely through its support for the National Indigenous Australians’ Sexual Health Strategy. The Centre has also provided technical support to the Tri-state Program in Central Australia. Although the Centre’s contribution may not have been as extensive as envisaged by the previous Review Panel, it has made substantial contributions, in keeping with its expertise and recognising that substantial progress across the health care system may enable further contributions.

**The relationship between the Centre and the University of New South Wales**

The Centre is an off-campus centre of the University of New South Wales Faculty of Medicine; it uses its own funds to rent accommodation. Staff of the Centre carry a considerable graduate teaching burden. There are no directly funded tenured posts, but two to four computer and administrative staff are funded by the University. Academic career development within the University and the promotion of Centre staff, particularly the program heads carrying out clinical trial work, was of concern to the Review Panel. Discussions should begin between the Centre and the University to redefine their relationship, with input from other appropriate authorities. These discussions should take into account the long-term vision for the Centre.

**The previous review**

The Centre was last reviewed in 1997, and the reviewers made 26 recommendations (see Section 7.6 (Appendix C)). The current Review Panel assessed the Centre’s performance in the light of these recommendations and was completely satisfied that, with four exceptions, the recommendations had been fully implemented. The four exceptions are:

- The Centre should continue and strengthen its work in relation to Indigenous people as one of its highest priorities. (recommendation 3)

- Health services research undertaken by the Centre should encompass cost-effectiveness studies and studies regarding compliance with prophylactic and therapeutic regimens. (part of recommendation 6)

- The expertise of the Centre should formally be brought to the attention of AusAID and … AusAID [should] be encouraged to utilise the expertise available in the Centre. (recommendation 25)

- Discussion should be undertaken with AusAID during the current review of AusAID’s Health Program to clearly delineate the relative expectations and responsibilities of AusAID and the Centre in relation to training and other assistance to countries in the Western Pacific and South East Asian regions. (recommendation 26)

These matters are discussed later in this report.
7.1.2 Recommendations

The following is recommended:

145. That a third level of management in the Centre be introduced.

146. That the Scientific Advisory Committee be streamlined, so that it provides the scientific guidance the Centre needs and that alternative mechanisms be explored for expanding the contribution of collaborators, stakeholders and other experts to the Centre’s work.

147. That in the next five years the Centre receive core funding that takes into account annual inflationary costs and the Centre’s expanding surveillance functions (see also recommendation 151).

148. That the Centre identify or develop national expertise in anti-retroviral pharmacology to support this area of research.

149. That the Centre conduct trials in hepatitis C–infected injecting drug users in collaboration with providers of their long-term care.

150. That the Centre explore, through further national and international collaboration, use of its unique repository of specimens on HIV-infected patients.

151. That the small amount of additional core funding for hepatitis C and B surveillance be extended for five years, taking into account annual inflationary costs. Expansion into the area of STIs, with improvements in the quality of data, will require additional core funding.

152. That support be sought from AusAID for expansion of the program in the Asia–Pacific region and preparation for the vaccine work. It may be necessary for the Centre to work with other groups in Australia who have a longer history of working experience in developing countries.

153. That the Centre continue to expand its work on Indigenous Australians’ health, including hepatitis C, through its work with the Indigenous Australians’ Sexual Health Committee and in collaboration with other research and health service provider organisations with expertise in Indigenous health.

154. That discussions begin between the Centre and the University of New South Wales to redefine their relationship, with input from other appropriate authorities. These discussions should take into account the long-term vision for the Centre.

155. That the Centre consider changing its name in the light of its current and future activities.
7.2 THE REVIEW PROCESS

The members of the Review Panel were:

Chair: Professor Ian VD Weller  
Department of Sexually Transmitted Diseases  
Royal Free and University College Medical School, London

Members: Professor Roel A Coutinho  
Municipal Health Service  
Amsterdam and Academic Medical Centre/University of Amsterdam

Dr Cathy Mead  
National Public Health Partnership, Melbourne

Secretariat support was provided by Ms Deb Sullivan, Flinders Medical Centre, Bedford Park, South Australia.

Professor Peter McDonald, Chair of the Clinical Trials and Research Committee of the ANCAHRD was available to provide advice.

The Terms of Reference for the review are set out in Section 7.4 (Appendix A).

The Centre was required to make a written submission to the Review Panel in April 2002, in the format of an NHMRC Program Grant, detailing projects, achievements and future plans.

Three independent experts were asked to assess and rate the achievements, research plan and team, and cooperation based on the Centre’s submission. The Centre was subsequently given the opportunity to reply to each assessor’s report.

The Review Panel reviewed the following documents:

♦ the submission by the National Centre in HIV Epidemiology and Clinical Research (April 2002)

♦ annual reports from the Centre (1998 to 2001)

♦ the report of the third review of the National Centre (October 1997)

♦ the Review of Australian HIV/AIDS Research (August 1999)


♦ the National Hepatitis C Strategy 1999–2000 to 2003–04


Submissions were sought from stakeholders and interested parties. Written submissions were received from:

♦ the Victorian Department of Human Services
♦ the New South Wales Department of Health
♦ the Australian Federation of AIDS Organisations
♦ the Australian Hepatitis Council
♦ the University of New South Wales
♦ the Australian Liver Association of the Gastroenterological Society of Australia
♦ the National Drug and Alcohol Research Centre
♦ the Department of Clinical Immunology and Biochemical Genetics, Royal Perth Hospital
♦ the Australasian Society for HIV Medicine
♦ the US National Institutes of Health, Department of Health and Human Services
♦ the Australian Injecting and Illicit Drug Users League
♦ the National Drug Research Institute
♦ the Australian Red Cross Blood Service
♦ the Inter-governmental Committee on HIV/AIDS, Hepatitis C and Related Diseases
♦ Queensland Health
♦ Queensland Health’s Community Services Program, the Prince Charles Hospital Health Service District Sexual Health and AIDS Service
♦ the Clinical Trials Group, UK Medical Research Council
♦ the US Department of Veterans’ Affairs Community Programs for Clinical Research on AIDS
♦ the South Australian Department of Human Services
♦ People Living with HIV/AIDS (NSW) Inc.
♦ the Burnet Institute for Medical Research and Public Health Ltd
♦ the National Association of People Living with HIV/AIDS
♦ the Indigenous Australians’ Sexual Health Committee, ANCAHRD
♦ the Office for Aboriginal and Torres Strait Islander Health.

The Review Panel met with the executive team and program heads of the National Centre in HIV Epidemiology and Clinical Research on Monday 2 June 2002 and continued its deliberations on Tuesday 3 June.
An oral report of the Panel’s findings and provisional recommendations was presented by the Chair, Professor Ian Weller, to the Strategy Research Review Team on 4 June 2002. The report was finalised following this meeting and submitted to the Review Team on 6 June 2002.
7.3 THE REVIEW PANEL’S FINDINGS IN DETAIL

7.3.1 Management of the Centre

Internal

The National Centre in HIV Epidemiology and Clinical Research has 70 full-time-equivalent staff (there were 38 in 1997) and 26 of these are academic staff (11 in 1997). Earlier this year the Centre’s internal management was restructured into six programs, each with a program head, and a finance and administration unit (see Section 7.7 (Appendix D)).

All the program heads meet with the executive committee twice a month. The meetings cover research and administrative matters alternately. Each program has its own research meeting and there are several joint programs.

The revised structure has given greater responsibility to a group of younger, talented researchers and clarifies their roles as research program heads. The Centre is well aware of the need now for a third tier of management, particularly in the case of the Therapeutic and Vaccine Research Program, which is the largest program by far.

Recommendation 145

That a third level of management in the Centre be introduced.

External

Most of the recommendations of the previous review have been implemented, and a Scientific Advisory Committee has been established. However, this group is large and constituted in such a way as to provide stakeholder input as well as high-level scientific advice in the development of the Centre’s programs and initiatives. As a result, it has not achieved all that the Centre staff had hoped.

Additional mechanisms may need to be explored to expand the contribution of external expertise while not diminishing the input of stakeholders, particularly those from the community sector. The possibility of holding annual scientific forums with collaborators, working group leaders, community representatives, and some international experts should be explored. If such forums were held regularly the Scientific Advisory Committee could be streamlined to provide the scientific guidance and critique that the Centre needs.

Alignment of IGCAHRD as a subcommittee of the Communicable Diseases Network Australia, which in turn reports to the National Public Health Partnership, provides an opportunity for the surveillance activities to be better integrated with broader communicable diseases surveillance and control functions.

Recommendation 146

That the Scientific Advisory Committee be streamlined, so that it provides the scientific guidance the Centre needs and that alternative mechanisms be explored for expanding the contribution of collaborators, stakeholders and other experts to the Centre’s work.
7.3.2 Funding

Since the last review, the Centre has attracted substantial funding from new sources, most notably the US National Institutes of Health. However, the core funding (A$3.7 million in 2002, compared with $3.34 million in 1997) is not keeping pace with costs—for example, staff costs and the cost of expansion into new areas of infrastructure. This could over time erode the Centre’s capacity to compete as successfully as it does for external funding, and it will diminish the quality of core functions such as surveillance, clinical trials infrastructure and administration. The Centre has only recently become eligible to apply for NHMRC funding, and it can be expected that its success in this area will grow, given its track record in attracting external funds. The Centre’s dependence on private sector funds, noted in the last review, has shifted substantially to international public sector funds.

Models for maintaining and expanding the funding of the Centre’s core infrastructure were discussed. The model of ‘deblocking’ centres previously block-funded under the NHMRC is not appropriate for this Centre because the core funding supports infrastructure programs such as surveillance and the development and maintenance of the clinical trials network, which are unlikely to be funded in a competitive system based on funding of investigator-initiated research. Other models of funding need to be explored. In addition, discussion of ‘mainstreaming’ is not particularly relevant for a Centre whose core functions are not funded by ‘mainstream’ research funding bodies. The model of funding surveillance as an integral part of a national research centre could be considered a mainstream model.

The Centre’s competitiveness internationally in attracting National Institutes of Health funds, amounting to US$20 million over five years, illustrates the substantial return on the investment through core funding.

Support for the Centre’s expanding surveillance functions has been minimal and this needs to be remedied if the surveillance strategies for hepatitis C and B and STIs are to be implemented.

Recommendation 147

That in the next five years the Centre receive core funding that takes into account annual inflationary costs and the Centre’s expanding surveillance functions (see also recommendation 151).

7.3.3 The Therapeutic and Vaccine Research Program

Therapeutic research

The Therapeutic and Vaccine Research Program is the Centre’s largest research program, with 21 full-time-equivalent staff (11 academic) and 11 external staff research nurses. The Program has a large number of project teams with cross-program membership (for example, the Biostatistics and Laboratory Programs) and these teams involve external investigators.
The Program’s objectives are to evaluate new treatments, new treatment strategies and candidate HIV vaccines and to conduct other studies of HIV’s natural history and treatment-related side-effects. The Program has over 30 clinical trials in progress or to be started in Australia and through the HIVNAT collaboration in Thailand. There is a balanced mix of investigator-initiated studies, multinational studies and pharmaceutically driven studies.

Through this Program the Centre has continued to raise its profile as one of the leading clinical trial centres in the world. It not only participates in pivotal international studies but also has shown great leadership in moving agents such as interleukin-2 through early exploratory trials to phase III assessment in multinational studies involving thousands of patients.

Essential to the Program’s success is the network of investigators in hospitals and general practice across Australia. In the last year 1200 patients (some 15 per cent of people known to be living with HIV infection in Australia) were in clinical trials at 40 sites, and Program staff had direct responsibility for the management of research protocols in other countries that have recruited 1500 patients. The Review Panel viewed this as a remarkable achievement.

The 1997 Review Panel recommended that health services research done by the Centre encompass cost-effectiveness studies. This research would require the Centre to provide relevant data to a health economist in Australia who was motivated to establish a research program in this area. This has not occurred.

**Vaccine research**

The Centre is the lead site of a national consortium that was successful in gaining A$27 million funding from the National Institutes of Health to develop and clinically test a prophylactic HIV vaccine. It is one of only a small number of AIDS vaccine projects worldwide that have received National Institutes of Health funding. A consortium of Australian researchers has developed a prime and boost vaccine technique, and the Centre is leading the consortium in the clinical evaluation with a phase I/II proof-of-concept study to evaluate immunogenicity and safety. A more expanded phase II study will be conducted in Thailand, and a vaccine preparedness cohort and related infrastructure will be established in readiness for a definitive phase III efficacy study should the earlier phase studies prove sufficiently promising.

**HIV-associated lipodystrophy**

The Centre’s research network was among the first in the world to characterise and report the lipodystrophy syndrome in 1998. It has since undertaken seminal studies to describe the syndrome’s prevalence, incidence and biochemical aspects, as well as approaches to treatment and clinical management.

**Pharmacology**

An important area of developing research is in the pharmacology of anti-retroviral drugs. Metabolism of these drugs is complex, with substantial intra- and inter-patient variability in pharmacokinetics. There are also important drug-drug interactions that are yet to be fully elucidated. The Centre wishes to begin a program in this area but has yet to develop or identify ‘home-grown’ pharmacological expertise.
Recommendation 148

That the Centre identify or develop national expertise in anti-retroviral pharmacology to support this area of research.

7.3.4 The HIV Epidemiology and Prevention Program

At the global level the majority of HIV infections are heterosexually acquired, but in Australia about 80 per cent of infections occur among men who have sex with men. As a consequence, the Centre has concentrated its research efforts in epidemiology on this group, studying both behavioural and biological risk factors, often in collaboration with the National Centre in HIV Social Research. A new cohort of high-risk HIV-negative gay men has been established, and among recent seroconverters risk factors of infection have been identified; this has helped guide intervention campaigns among men who have sex with men in Australia. Additionally, an observational study of drug side-effects and compliance was established among people receiving post-exposure prophylaxis after non-occupational exposure to HIV. Internationally recognised studies have been done on HIV-related cancers because of the Centre’s ability to link the national HIV database with the cancer registry. This link is not available in many other countries. A large non-progressors cohort has been established.

The Centre plans to continue its study of risk factors for recent infection. A Phase III vaccine preparedness study will be started, funded through the grant obtained from the National Institutes of Health. This study will enrol about 2000 men who have sex with men, from whom epidemiological information will be collected and blood stored. If funding is obtained, apart from HIV testing, testing will be carried out for other blood-borne and STIs, such as hepatitis C, HHV-8, *Chlamydia trachomatis* and gonorrhoea. For non-occupational exposure, a randomised controlled trial of a single drug, tenofovir, is under consideration. The linkage studies on HIV-related cancers will also continue, concentrating on long-term HIV-infected people. The non-progressors cohort will be expanded and will remain an important source for national and international in-depth virological and immunological laboratory studies, which will attempt to identify viral and host factor mechanisms for non-progression.

Collaboration with the National Centre in HIV Social Research

In both the Surveillance and the Epidemiology Programs of the Centre there is collaboration with the staff (particularly quantitative social scientists) of the National Centre in HIV Social Research, which is also part of the University of New South Wales but at a different location and in a different faculty. Such collaboration is considered essential for both parties; it should be maintained and, if possible, strengthened—for example, by joint appointments between the two Centres.

7.3.5 The Viral Hepatitis Program

In the past the Centre has used its HIV expertise to extend its activities to viral hepatitis B and C, concentrating on surveillance of these infections and studying risk factors and long-term sequelae. These studies have been important for better estimating the burden of these infections and have assisted in the development of public health programs for the prevention,
treatment and care of hepatitis B and C infection in Australia. Internationally recognised studies have been done on the natural history of chronic hepatitis C infection in both HIV-negative and HIV-positive people.

The Centre will use its knowledge and experience in HIV clinical trials to increase its contribution to therapeutic research into viral hepatitis. The studies will be done in close collaboration with the Australian Liver Association and other partners through the recently established Viral Hepatitis Working Group. This work will not only be undertaken with industry sponsorship but also by investigator-led grants. Risk factors for hepatitis C transmission will be studied in both injecting drug users and other groups. The Centre is involved in evaluating the effectiveness of medically supervised injecting and other harm-reduction programs aimed at preventing hepatitis C (and HIV) transmission. A prospective cohort of people with newly acquired hepatitis C infection will be established so that the natural history of primary infection and the effects of therapy can be studied. A grant application for this study has been submitted to the US National Institute of Drug Abuse. Long-term sequelae of hepatitis C infection will be studied using several approaches: a retrospective cohort study; meta-analysis of the literature; and the establishment of an observational database. Another research objective is to measure the quality of life in people with chronic hepatitis C infection.

The Viral Hepatitis Program has great promise, especially because of the Centre’s experience with multicentre trials of HIV anti-retrovirals. Until now work has mainly involved trials among gay men, who are known to be highly compliant and in whom follow-up is good. Experience should be gained in setting up similar trials among the most important hepatitis C risk group—injecting drug users. Such studies can be done only in collaboration with the people who provide long-term care for injecting drug users.

Recommendation 149

That the Centre conduct trials in hepatitis C–infected injecting drug users in collaboration with providers of their long-term care.

7.3.6 The Primary HIV Infection Program

The Primary HIV Infection Program is another area where the Centre has been recognised as an international leader. Its success rests on its ability to identify early infection, using its national network of investigators; on-site, rapid laboratory testing; its laboratory support and research program; and the repository of stored material from patients. This is an example of the Centre’s interdisciplinary strength. The future program aims to cover:

♦ the natural history of early immunological changes and their correlation with viral set-points and disease progression

♦ the effect of treatment—structured treatment interruptions and therapeutic vaccination—on these responses

♦ the transmission of drug-resistant viruses.
Just before this review the Centre was awarded National Institutes of Health support of US$3.67 million over five years for components of this work to be carried out with Harvard University in the Acute Infection and Early Disease Research Program.

### 7.3.7 The Biostatistics and Databases Program

The primary role of the Biostatistics and Databases Program is to support developments across the breadth of the Centre’s work: approximately 75 per cent of the Program’s resources provide this support. Key directions for the future include modelling, supporting observational databases, methodology developments, and database support.

The Australian HIV Observational Database has been established for two years; the national clinical trial network of hospital and general practitioner sites enabled its establishment. In the absence of randomised clinical trials, observational databases are the next in line in the hierarchy of evidence for treatment effects. The Database is contributing to large international efforts. The Data Collection on Adverse events of Anti-HIV Drugs (DAD) study is a prospective study—initiated by the European Medicines Evaluation Agency—in more than 19,000 HIV-infected patients—examining the possible association of antiretroviral therapy and premature cardiovascular disease. The Performance of Lopinavir/Ritonavir as an Alternative Treatment Option (PLATO) study is a similar study, evaluating the effects of salvage therapy in patients whose treatment options are limited. The Centre plans to establish a hepatitis C observational database in Australia and an HIV observational database in Asia. The Program leader serves on the steering committee of the international cohort studies and provides statistical advice.

This Program illustrates the importance of a biostatistical infrastructure investment in attracting substantial additional funding in the national and international contexts.

### 7.3.8 The Laboratory Program

The Laboratory Program is based on the combined resources of the Centre, the laboratories at the St Vincent’s Hospital campus, and the New South Wales State HIV Reference Laboratory. An excellent additional laboratory facility was incorporated in the Centre’s organisation when space became available in the Garvan Institute and the new Program Head returned from postdoctoral studies in Oxford, UK.

**Service and support for other programs**

In the last five years the Program has accommodated an annual average of 1200 requests for cell storage, 2600 for serum or plasma storage, and over 400 for processing of other specimens involving lymphoid tissue, serum and cerebrospinal fluid for the other Centre programs. It also provides non-routine assays such as extended flow cytometry panels.

**Transitional and pathogenesis research**

Transitional and pathogenesis research is being carried out mainly in the context of natural history studies and clinical trials.
New assays for antiviral resistance, immunophenotyping and functional assays have been validated and then moved into routine or semi-routine use. Work of this kind will continue. Immunogenicity assays will be used in support of the prophylactic vaccine studies, and novel techniques such as the synthesis of MHC class II tetramers to study antigen-specific CD4+ T-cell responses are being developed in collaboration with the University of Oxford.

Pathogenesis research will be in the areas of primary infection, examining antigen-specific T-cell turnover; the time course of plasmacytoid dendritic cell depletion, its functional implications and the effect of therapy; the mechanisms and implications of immune escape; and novel resistance mutations outside the pol and protease genes.

**A national resource**

The repository of specimens is an important national resource. There is ample evidence of this in the repository’s use by external investigators—for example, Martyn French (Perth), collaborating on the Initio substudy; Stephen Kent (Melbourne) and Rose French (Sydney), within the vaccine collaboration; Simon Mallal (Perth), working on the supply of primary infection sequences; Robert Oerlichs (Melbourne), working on seroconverter samples for phylogenetic analysis; and Wayne Dyer and John Sullivan (Sydney Blood Bank) and Tony Cunningham and Nitkin Saksena (Westmead), working on long-term non-progressors.

**Support for the HIVNAT program in Thailand**

The Laboratory Program has overseen the establishment of a laboratory support program for the clinical trials and studies encompassed by the HIVNAT collaboration in Thailand and continues to audit laboratory standards. Encouragingly, this has led to a rolling-out of expertise, with Thai scientists upgrading other Thai laboratories.

**Recommendation 150**

That the Centre explore, through further national and international collaboration, use of its unique repository of specimens on HIV-infected patients.

**7.3.9 Surveillance**

The Surveillance Program, under the supervision of the Deputy Director, to a large extent occurs within other programs.

The Centre has substantial expertise in the development of surveillance under the Australian federal structure and the legal frameworks operating in the states and territories. The three areas of HIV/AIDS, hepatitis C and B, and STIs are in various stages of development, as shown in Section 7.8 (Appendix E).

Among the directions for future development are newly acquired HIV infections, expansion of surveillance activities in hepatitis C and B, and the development of national STI surveillance, beyond the current passive surveillance to a National STI Surveillance Strategy under the auspices of the Communicable Diseases Network Australia. The annual surveillance report is a key output from this Program.
Surveillance is one of the Centre’s primary functions. Expansion into the area of STIs, with improvements in the quality of data, will at some point require additional core funding so that the developing National Strategy can be implemented. Some supplementation has been provided for hepatitis C and B; this needs to continue.

For STI surveillance, a close relationship with STI physicians and other parties will be required. This could be achieved through a model similar to the Viral Hepatitis Working Group.

Given the Centre’s expertise in surveillance and the investment made in developing this capacity, there is scope for expansion of activities beyond the current areas. The Centre has already made a contribution, for example, to surveillance of Creutzfeldt–Jakob disease. Expansion to other infectious diseases would require greater integration between the Centre’s surveillance activities and expertise and work being done under the auspices of the Communicable Diseases Network Australia.

The National Public Health Partnership has recently decided to streamline reporting arrangements and has designated the IGCAHRD as a subcommittee of the Communicable Diseases Network. The Partnership has also asked that IGCAHRD oversee development work on a national approach to STI control. It sees chlamydia as an initial priority for this work.

**Recommendation 151**

That the small amount of additional core funding for hepatitis C and B surveillance be extended for five years, taking into account annual inflationary costs. Expansion into the area of STIs, with improvements in the quality of data, will require additional core funding.

### 7.3.10 Work in the Asia–Pacific region

The Centre has played an important part in establishing in Bangkok a clinical trial centre that is now able to conduct HIV therapeutic trials of international standard. The experience gained could be used for future HIV vaccine trials, since this is a direction the Centre is pursuing. However, Thailand is involved in several vaccine trials (phases I, II and III) and there may be insufficient capacity to perform additional trials in that country, especially phase III efficacy trials. Setting up HIV vaccine trials in other (developing) countries in the region will require long and intensive preparation, both to establish the necessary infrastructure and to avoid tensions. Experience in Thailand, and in African countries, shows that vaccine trials are possible only if the medical professionals, politicians and communities involved support them. The Centre is therefore well advised to start the necessary preparations for HIV vaccine trials in developing countries in the region—not only for phase III trials but also for phases I and II. Support from AusAID should be sought for this infrastructure- and capacity-building work, and it may be necessary for the Centre to work with other groups in Australia with a longer history of experience in developing countries.

**Recommendation 152**

That support be sought from AusAID for expansion of the program in the Asia–Pacific region and preparation for the vaccine work. It may be necessary for the Centre to work with other groups in Australia who have a longer history of working experience in developing countries.
7.3.11 Indigenous Australians’ sexual health

The previous review recommended that Indigenous Australians’ sexual health become one of the Centre’s highest priorities.

The Centre’s contribution in this regard comes largely through its support for the National Indigenous Australians’ Sexual Health Strategy. The Indigenous Australians’ Sexual Health Committee is also represented in working groups, including the Scientific Advisory Committee and the Communicable Diseases Network Australia STI surveillance committee. In addition, the Centre has provided technical support to the Tri-state Program in Central Australia.

Areas of future work include improving surveillance, involvement of communities in all areas of the Centre’s work and, in particular, developing contributions that reflect the Centre’s expertise. This would involve working with urban communities and injecting drug users, in partnership with others, and involving communities and individuals in treatment trials. Further work on national STI surveillance could lead to expanded research capacity in relation to STIs relevant to Indigenous communities.

Although the Centre’s contribution may not have been as extensive as envisaged in the recommendation of the 1997 review, it has contributed in keeping with its expertise and recognising that substantial progress across other areas of the health system may enable further contributions. Involvement of Indigenous people and communities in clinical trials, particularly hepatitis C trials, could become a significant contribution.

**Recommendation 153**

That the Centre continue to expand its work on Indigenous Australians’ health, including hepatitis C, through its work with the Indigenous Australians’ Sexual Health Committee and in collaboration with other research and health service provider organisations with expertise in Indigenous health.

7.3.12 University collaboration

The Centre is an off-campus centre of the University of New South Wales Faculty of Medicine; it uses its own funds to rent accommodation. In contrast, the University has provided a permanent home for the National Centre in HIV Social Research through the Faculty of Arts and Social Sciences. The University’s submission to this review acknowledges the unique contribution the National Centre in HIV Epidemiology and Clinical Research is making and the value of its association with the University. Staff of the Centre carry a considerable graduate teaching burden and, in addition to masters courses, 27 higher degree students have completed their theses under the supervision of Centre staff. Further, there are no directly funded, tenured posts within the Centre. Two to four computer and administrative staff are funded from the return by the University Research Infrastructure Block Grant/Research Quantum.

Academic career development within the University and the promotion of Centre staff, particularly the program heads carrying out clinical trial work, was of concern to the Review Panel. This is important in terms of these people’s national and international recognition. In addition, academics working in large clinical trials spend a large amount of time in
facilitatory and developmental work. A ‘single experiment’ can take several years. Production of a single publication represents considerable scientific endeavour, with an authorship that often hides the contribution of the ‘main players’. As a result, the publication output of a clinical trial scientist cannot compete with that of other clinical and basic scientists.

These difficulties with the relationship between the Centre and the University should be taken into account in the long-term vision for the Centre.

**Recommendation 154**

That discussions begin between the Centre and the University of New South Wales to redefine their relationship, with input from other appropriate authorities. These discussions should take into account the long-term vision for the Centre.

**7.3.13 Centre name**

**Recommendation 155**

That the Centre consider changing its name in the light of its current and future activities.
7.4 APPENDIX A  THE REVIEW PANEL’S TERMS OF REFERENCE

Following are the Terms of Reference for the Review Panel:

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

♦ The current strategic planning processes, goals and priorities and progress made towards meeting the stated goals/priorities;

♦ 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;

♦ The extent to which the goals and activities reflect the needs of key stakeholders (ie Commonwealth and State/Territory policy makers, ANCAHRD, AFAO, Hepatitis C organisations, NAPWA, the medical and research communities (including ASHM), and Aboriginal people and Torres Strait Islanders);

♦ 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;

♦ 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.

♦ Evaluate the cost-effectiveness, utility and efficiency of hepatitis C and STI surveillance as carried out by the NCHECR.

Research dissemination and exchange

♦ The nature, appropriateness and effectiveness of Centre mechanisms for disseminating research findings and information policy developments.

♦ The extent and value of the collaboration of the Centres with researchers in the HIV/AIDS, hepatitis C and related areas (eg Drug and Alcohol Research Centres) and the Centres’ success in encouraging leading researchers to focus attention on HIV, hepatitis C and related research;

♦ 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, WHO and overseas universities/research centres.

♦ 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; and

– the capacity of existing Centres to attract and maintain external funding.

♦ 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

♦ Other matters considered relevant or which emerge during the review.
7.5 APPENDIX B  THE CENTRE’S TERMS OF REFERENCE

Following are the Terms of Reference for the National Centre in HIV Epidemiology and Clinical Research:

Research and surveillance

♦ To initiate, enhance, support and coordinate national surveillance for HIV/AIDS, blood-borne viruses and STDs in Australia in collaboration with State, Territory, Commonwealth and other relevant agencies.

♦ To initiate and carry out research into epidemiological and clinical aspects of HIV/AIDS, blood-borne viruses and STDs, including transmission, natural history and health services.

♦ To review, evaluate, co-ordinate, participate in and provide assistance for clinical trials of therapeutic substances for the treatment of HIV/AIDS.

♦ To develop collaborative research related to the Centre’s primary areas of activity internationally, particularly in the Asia-Pacific region.

Leadership and research resources

♦ To maintain close liaison and collaboration with the National Centre in HIV Virology Research, the National Centre in HIV Social Research, the National HIV Reference Laboratory and other collaborating centres including providing assistance in research design, development of data collection instruments, data processing and analysis and, to a limited extent, conducting research into natural history studies and the clinical aspects of blood-borne viruses and STD infection.

♦ To inform the development and implementation of policy and practice with respect to prevention and to the management of the HIV/AIDS epidemic.

Training and education

♦ To provide tangible opportunities and encouragement for postgraduate and post-doctoral training of scientific and medical staff in the epidemiology of HIV/AIDS, blood-borne viruses and sexually transmitted diseases.

♦ To disseminate the results of the Centre’s research through all possible means, including presentations at national and international meetings, publications, through the media, and in an annual report and to support the dissemination of epidemiological and clinical knowledge related to HIV/AIDS, blood-borne viruses and sexually transmissible diseases to relevant communities.

Other

To perform other roles which may be determined from time to time by the Director, in consultation with ANCARD and approved by the Department of Health and Family Services.
7.6 APPENDIX C RECOMMENDATIONS OF THE PREVIOUS REVIEW COMMITTEE

The previous review committee made the following recommendations:

1. The National Centre should receive core funding for the next five years to continue its work, with the next Review to be undertaken in 2002.

2. The Terms of Reference for the Centre should be amended in line with Section Seven of this report.

3. The Centre should continue and strengthen its work in relation to indigenous people as one of its highest priorities.


5. The Sydney Men and Sexual Health (SMASH) cohort study should be stopped when the remaining proportion of the original cohort reaches 45 per cent. More representative behavioural information should be obtained by repeat cross-sectional studies.

6. Health services research undertaken by the Centre should encompass cost-effectiveness studies and studies regarding compliance with prophylactic and therapeutic regimens. The spectrum should encompass HIV/AIDS, hepatitis C virus (HCV) and, where appropriate, sexually transmitted diseases. The latter work should be consistent with the principles set out in the Third National Strategy.

7. The laboratory facilities and technical support staff to process, archive and, in the long term, maintain tissue samples, plasma, serum cells, DNA, RNA and viral isolates from individuals, cohorts or clinical trial participants should be separately funded and co-ordinated with the National Centre in HIV Virology Research. Funding, model rules of access and ethical principles related to the use of the materials should be clarified as a matter of some urgency.

8. An information strategy should be developed that supports the production of computer software incorporating an agreed set of data fields of relevance to studies of natural history, transmission, treatments and demographic features of HIV/AIDS. It is envisaged that baseline and annual data could be acquired, stored electronically at the site of care and, subject to the requirements of public health regulations and with appropriate consent of patients, used for research in approved projects.

9. An agreed set of demographic and clinical data should also be acquired for any laboratory research samples stored in the course of clinical or epidemiological studies. Data should include information regarding consent, sample collection conditions, timing, processing, de-identification coding, rules of access and guards to confidentiality.

10. Where opportunities exist, HIV natural history studies (in their broad sense including modification by treatment) should be conducted in ethnic-specific groups including indigenous Australians.

11. The Committee endorsed the view of the 1992 Review panel that the Community Health Research Network (CHRN) becomes an integral part of the Centre’s program and management structure.

12. The Clinical Trials Working Groups should report directly to the Director of the Centre. The Director should be required to report to the Scientific Advisory Committee on any concerns raised by community representatives on the Working Groups.
13. The Centre, in addition to continuing its trials of new therapies, should increasingly address the important strategic questions in combination antiretroviral therapy.

14. Consideration should be given to convening a meeting of participants from all constituencies of the treatments community to discuss the advantages and disadvantages of observational databases in defining treatment strategies and regimens associated with improved outcomes.

15. There should be one Scientific Advisory Committee (SAC) for the National Centre, with responsibility for scientific standards and strategic planning of the Centre. Its composition should primarily reflect the scientific expertise needed to give appropriate guidance and advice to the Centre, as well as appropriate representation from the community, ANCARD and host institutions.

16. The SAC should take responsibility for advice and guidance of all aspects of the Centre’s work, including clinical trials, with sub-committees established only where necessary to undertake detailed development of specific areas, for example in relation to non-HIV surveillance.

17. The Centre should produce a five-year rolling strategic plan, under the guidance of the SAC. This plan should be aligned with a budget that is presented in program format.

18. The Director should provide an annual report to ANCARD, endorsed by the SAC, and via RAC, on the progress of the Centre towards achieving its strategic goals.

19. Treatments advice should be the responsibility of a sub-committee of ANCARD, and responsibility for the clinical trials program and CHRN should be vested in the SAC.

20. The Clinical Trials and Treatments Advisory Committee (CTTAC) budget should be divided between clinical trials and treatments, with the clinical trials component being rolled into the Centre, and the treatments component allocated on the advice of the proposed Treatments Sub-Committee of ANCARD.

21. The current rules for application for Commonwealth competitively-awarded grants should continue to apply in relation to the core program of HIV research. Scope should be allowed for Centre staff to apply for grants to undertake research in related diseases or under special circumstances as approved by RAC. Initial expressions of interest should be examined by a joint committee of RAC and the NHMRC in order to make a ruling on eligibility.

22. The wording of the Third National Strategy should guide the activities of the Centre as far as the use of core funding to undertake work into related diseases is concerned i.e. those areas ‘… that have a clear and direct overlap with HIV/AIDS prevention strategies or target groups or are co-factors in HIV transmission’.

23. The Centre should be allowed to tender for work into related diseases such as hepatitis C and sexually transmitted diseases, particularly the co-ordination of national surveillance and natural history studies. These activities should be supported through commissioned or competitive project grants.

24. The Centre’s role in the Asia-Pacific region should be encouraged and endorsed provided that the major efforts and resources put into such roles is limited to a small proportion of Centre core resources and that the majority of such activities are in the area of HIV.

25. The expertise of the Centre should formally be brought to the attention of AusAID and that AusAID be encouraged to utilise the expertise available in the Centre.
26. Discussion should be undertaken with AusAID during the current review of AusAID’s Health Program to clearly delineate the relative expectations and responsibilities of AusAID and the Centre in relation to training and other assistance to countries in the Western Pacific and South East Asian Regions.
### 7.8 APPENDIX E CURRENT STATUS OF SURVEILLANCE

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* STI clinics, blood donors, Defence Force.
** Injecting drug users.

Note: Work on standardising case definitions and risk factor recording is in progress for HCV. The work on hepatitis B virus (HBV) and STIs has just been initiated.
8.1 Recommendations

Recommendations from the Lead Review Team Report

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.

6. 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.

7. 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.

8. Development of a whole-of-government policy on Australia’s role and responsibilities in relation to the international HIV epidemic

9. Review and implement other recommendations of the HIV Strategy Review Team, consistent with the recommendations of the Lead Review Team.

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.

10. 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.

11. 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 buperonorphine
   ♦ 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.

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.

24. For the Population Health Division, convene, at least yearly, round tables of stakeholders, to identify and set priorities for strategic research.
25. 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.

26. Begin negotiations to identify funding for and a process for establishing a research program for hepatitis C.

27. Monitor the funding transition process to ensure that relevant strategic research is not interrupted.

28. Review and implement all specific recommendations of the Strategic Research Review Panel, consistent with the recommendations of the Lead Review Team.

29. 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.

30. 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).

31. 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.

32. 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.

33. 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.

Recommendations from the Review of the National HIV/AIDS Strategy

The HIV/AIDS Review Panel recommends as follows:

31. That a major new national education program on prevention be developed with the states and territories and key stakeholders—for the term of a fifth National HIV/AIDS Strategy and beyond—to decrease rates of unprotected anal intercourse, related STIs (gonorrhoea and chlamydia) and HIV transmission among men who have sex with men. This program should include, among other things:

♦ development and enforcement of agreed codes of conduct within all ‘sex on premises’ venues—including prevention education, condom distribution, promotion of HIV and STI counselling and testing, and promotion of non-occupational post-exposure prophylaxis for men

♦ development of new communication and community-based programs to reach young gay men, men who have sex with men but are not attached to the gay community, and gay men living in rural and remote areas

♦ development of a national annual sexual health check-up program for men who have sex with men, along with continuing public campaigns to increase the availability of and participation in counselling and testing

♦ review and updating of HIV-testing guidelines.

30. That harm-reduction approaches, in their broadest sense, be strongly supported from the funding and policy level-perspectives. This includes:

♦ needle and syringe programs
  - development of best-practice models for needle and syringe programs—for example, referral systems and local community management systems involving police, traders, residents, pharmacists, local government, non-government organisations and magistrates courts
  - support for expanded hours
  - provision of sterile water
  - workforce development

♦ availability of medical detoxification

♦ a broad range of substitution therapies—methadone, buperonorphine, and so on

♦ availability of abstinence-based therapies

♦ connections to and from the prison systems—see also recommendation 32
Recommendations

♦ peer education programs
♦ an education program for decision makers and the general community.

31. That new approaches to harm reduction—such as the use of supervised injecting facilities, syringes with retractable needles, and medically prescribed heroin—be rigorously evaluated.

34. That, in close collaboration with the states and territories, a national HIV prevention and care program for prisons be developed. This should include:
♦ increased availability and uptake of both substitution-based and abstinence-based treatments for drug users in prisons
♦ strong continuing engagement with prison officers and their unions to develop programs—for example, in-prison needle and syringe exchange programs—that benefit the officers as well as the prisoners.

33. That culturally and linguistically diverse communities at high risk of HIV transmission be added to the other priority groups in the current Strategy—Aboriginal and Torres Strait Islander peoples, people who inject drugs, people in custodial settings, sex workers, and the male and female partners of these people—and that a national program be developed with the states and territories to reduce transmission in these communities.

34. That the next-generation national program of epidemiological, behavioural and clinical surveillance be developed. This should include new testing technologies, such as the detuned ELISA test, and indicators such as HIV testing patterns, viral load, unprotected anal intercourse, condoms, and needles and syringes.

35. That one of the main performance indicators for the National Centre in HIV Epidemiology and Clinical Research be the extent to which the Centre builds surveillance capacity with the states and territories.

42. That a national workforce-development program be designed and implemented with the states and territories and key stakeholders.

43. That the Commonwealth revitalise its national leadership role through enhanced funding, policy development, research, overall coordination, support for the partnership, and international assistance.

38. That the current governance structure be dissolved and that four advisory committees be established—HIV, Hepatitis C, a Legal Committee, and an Indigenous Australians’ Sexual Health Committee—with coordination achieved through a committee of Chairs and Deputy Chairs.

39. That a Governance Charter be developed to clearly define the respective roles of the different elements of the new governance structures—for example, advisory committees, working groups and government departments.

40. That the Commonwealth Parliamentary Liaison Group be revitalised and supported and be seen as a very important element of the national response.

41. That consideration be given to developing a national strategy for STIs, to rekindle interest in working with Australia’s young people.

42. That a framework for continuing evaluation of the National HIV/AIDS Strategy be developed and implemented.
43. That a biennial, comprehensive study to identify, document and track over time the responses to HIV/AIDS at the national, state and territory and local levels be developed and carried out.

44. That resources be specifically dedicated to the establishment of new and continuing capacity to analyse and monitor the economic benefits and costs to government and the community of HIV programs and their components and sub-components.

45. That the National Centres in HIV Research commit increased effort and resources to understanding changing trends in unprotected anal intercourse, gonorrhoea and HIV infection in Victoria and South Australia.

46. That the agenda for the National Centres in HIV Research be set by means of a consultative process at three-year intervals, with provision for rapid responses to emerging problems as they arise.

47. That a cross-sectoral working group—with representation from the Department of Health and Ageing, AusAID, the Department of Foreign Affairs and Trade, and the Department of Immigration and Multicultural and Indigenous Affairs, plus co-opted external experts—be established to expand and coordinate Australia’s international role in HIV/AIDS. The working group should report to the HIV Committee of the new governance structure.

48. That the Department of Health and Ageing work with AusAID to develop a mechanism for improving the participation of Australian experts in our international response.

51. That task-focused, time-limited working groups—reporting to the HIV Committee—develop national approaches to complex cross-government questions such as:
   ♦ income support for people living with HIV/AIDS
   ♦ access to therapies
   ♦ models of care for people living with HIV/AIDS, including evaluation of the GP Enhanced Care Pilot Project in New South Wales
   ♦ mental illness services
   ♦ supported accommodation and housing for people living with HIV/AIDS
   ♦ Medicare ineligibility.

52. That a fifth National HIV/AIDS Strategy be developed to further develop and implement the foregoing recommendations. The Strategy should cover the three years from 2004–05 to 2006–07 and should be reviewed in mid-2006.

**National Hepatitis C Strategy Review**

The Hepatitis C Review Team recommends as follows:

51. That the partnership approach be reaffirmed as essential to an effective national response to hepatitis C and that the non-government and community sector’s capacity to respond be enhanced, so that the sector can participate more effectively in the partnership.

52. That new governance structures be developed to support the national response to hepatitis C.
53. That the states and territories review their governance structures for hepatitis C, so that they can develop equitable partnerships and match resources to identified needs.

54. That the National Public Health Partnership be expanded to include local government and non-government and community sector representation.

55. That the Commonwealth Parliamentary Liaison Group be revitalised and recognised as a very important element of the national response to hepatitis C.

56. That equitable, sustained funding be provided to develop and implement an effective response to hepatitis C in Australia at all levels—federal, state and territory, local government, and the non-government and community sector.

64. That the PHOFAs be used to ensure the allocation of a base level of resources and the setting of performance indicators for hepatitis C–related activity at the state and territory level.

65. That—in the light of the findings and recommendations of the November 2001 Anti-Discrimination Board of New South Wales enquiry into hepatitis C related discrimination—the Commonwealth and state and territory governments give priority to redressing hepatitis C–related discrimination in their jurisdictions.

66. That—on the basis of the experience of the New South Wales Hepatitis C Awareness Campaign—the Commonwealth support a national hepatitis C public awareness campaign to increase knowledge of and reduce the stigma associated with hepatitis C infection.

67. That the following harm-reduction strategies be strongly supported in a range of settings:
   ♦ NSPs
   ♦ medical detoxification
   ♦ substitution therapies—including methadone and buprenorphine
   ♦ abstinence-based therapies
   ♦ peer education programs.
   Newer initiatives such as supervised injecting facilities, medically prescribed heroin and retractable needle and syringe technology should be rigorously evaluated before they are expanded.

68. That the recommendations of the Australian National Council on Drugs position paper on NSPs be implemented in all jurisdictions.

69. That strategic and investigator-initiated research be recognised as fundamental to Australia’s response to hepatitis C and be equitably resourced.

70. That research be commissioned to:
   ♦ investigate the social and behavioural factors relating to hepatitis C transmission in a range of settings and contexts.
♦ help develop and guide a broad range of hepatitis C prevention and health-promotion activities at all levels—federal, state and territory, local government, and the non-government and community sector

♦ explore the treatment, care and support needs of people living with hepatitis C

♦ investigate the reasons for the low uptake of treatments in Australia

♦ determine the future hepatitis C treatments load relative to the burden of disease

♦ investigate the economic impact of hepatitis C infection in Australia, to account for any changes in costs associated with new treatments

♦ develop and evaluate models of care for hepatitis C in the context of a systematic focus on health services.

64. That the hepatitis C research priorities of ANCAHRD be reviewed and that, if necessary, a new set of priorities be established to direct funding.

65. That the Clinical Trials and Research Committee be abolished and that hepatitis C research be incorporated in the Hepatitis C Committee’s brief.

66. That the Commonwealth and the states and territories renew their commitment to hepatitis C surveillance.

67. That the Commonwealth continue its support for the hepatitis C–related surveillance activities of the National Centre in HIV Epidemiology and Clinical Research.

68. That the Communicable Diseases Network Australia:

♦ conduct an evaluation of the Australian Hepatitis C Surveillance Strategy as a matter of priority, noting the drawbacks of a surveillance system based on prevalence data and the difficulty of obtaining accurate data on hepatitis C incidence

♦ provide to the existing Hepatitis C Committee, and its successor under a second National Hepatitis C Strategy, an annual report on the implementation of the Australian Hepatitis C Surveillance Strategy.

69. That the annual NSP survey be expanded to include adults and juveniles in custodial settings.

70. That the Commonwealth lead a process, involving all key stakeholders, to review and create opportunities for more strategic and longer term links between the key national strategies referred to in Section 3.5 of the National Hepatitis C Strategy 1999–2000 to 2003–04.

72. That there be greater emphasis on ‘front-end’ processes to guide the development of hepatitis C strategies, policies and research agendas, including requirements for appropriate engagement of affected communities, collaborative planning processes, and the use of Indigenous advisory and reference structures.
72. That the capacity of all health services be enhanced so that they can address hepatitis C prevention, education, treatment, care and support for Aboriginal and Torres Strait Islander peoples.

73. That culturally appropriate strategies and resources to prevent hepatitis C infection and its consequences be developed with and for Aboriginal and Torres Strait Islander peoples, through the state- and territory-based Aboriginal Health Partnerships and the Aboriginal community-controlled health sector.

74. That culturally appropriate strategies and resources to prevent hepatitis C infection and its consequences be developed with and for people from culturally and linguistically diverse backgrounds.

75. That awareness of the availability and efficacy of hepatitis C treatments be increased by targeted information provision through primary care physicians, specialist liver clinics and NSPs.

76. That a range of models of care for different settings—custodial, rural, and so on—be developed, implemented and evaluated.

77. That equitable funding be provided to develop models of comprehensive primary health care for communities bearing a high disease burden.

78. That an audit of actual treatment response rates become a standard reporting requirement for the states and territories under the Highly Specialised Drugs Program (S100).

79. That a national hepatitis C workforce program be developed in consultation with all key stakeholders. Affected communities should be engaged in the design and delivery of this program.

80. That people with hepatitis C or at risk of infection and living in rural, regional and remote areas of Australia have equitable access to hepatitis C–related education and prevention interventions, appropriate health care services that ensure a continuum of care, and innovative models of care.

81. That the lessons learnt from the application of harm-reduction strategies in custodial settings in other countries be explored for implementation in Australia.

82. That custodial staff be provided with training in relation to hepatitis C, in the context of occupational health and safety.

83. That a national policy on the provision of pharmacotherapies for illicit drug dependence in custodial settings be developed for all jurisdictions.

84. That broad support be given to initiatives designed to divert people who use illicit drugs away from incarceration and into non-custodial alternatives.

85. That nationally consistent standards for hepatitis C education and prevention be implemented in custodial settings.
86. That—in close consultation with the people affected by hepatitis C, the community sector, the medical, health care, research and scientific communities, and all levels of government—the Commonwealth Department of Health and Ageing develop a second National Hepatitis C Strategy for the period 2004 to 2009, to further develop and implement the recommendations of this Review.

87. That a second National Hepatitis C Strategy:

♦ be framed in the context of communicable diseases but take a settings-based approach to health promotion

♦ be supported by dedicated funding, a detailed implementation plan with performance indicators, strong Commonwealth leadership, and new governance structures, including

- establishment of new, separate Committees for Hepatitis C, HIV and Indigenous Australians’ Sexual Health, with a strong focus on implementation of the respective Strategies through setting their own work plans and incorporation of research and health promotion in their agendas. The new Hepatitis C Committee would comprise people with expertise in legislative and regulatory reform, health promotion, illicit drugs, disease prevention, the non-government and community sector and affected communities (including representatives from relevant peak bodies), public health, treatments (including specialist clinical services, general practice and allied health professions), Indigenous Australians’ health, research, workforce development, and custodial settings

- establishment, by the new Hepatitis C Committee, of ad hoc working groups to deal with specific matters

- establishment of a new Ministerial Advisory Committee for Hepatitis C, HIV and Sexual Health, comprising the chairs of the three new Committees and one overarching chairperson. This Committee would have a primary role in advocacy and securing sufficient resources to enable effective implementation of the Strategies and would be responsible for equity and collation of information, with minimal oversight of the work of the three Committees

- the new Ministerial Advisory Committee to forge strong links with national governance structures for illicit drugs

♦ reaffirm the six essential components of Australia’s response to hepatitis C—developing partnerships and involving affected communities, access and equity, harm reduction, health promotion, research and surveillance, and linked strategies and infrastructures

♦ be supported by appropriate legislative and regulatory frameworks, including drug law reform and anti-discrimination, which are necessary because of the magnitude of the epidemic

♦ be supported by evidence-based strategies developed in all jurisdictions
♦ take account of the changes in diagnostics, treatment and care, and workforce
development that have occurred during the term of the first Strategy
♦ designate clinical outcome indicators for hepatitis C
♦ be monitored and evaluated in all jurisdictions
♦ be subject to an independent, external mid-term review.

88. That monitoring the impact of hepatitis C in the Asia–Pacific region and international
assistance and cooperation in respect of hepatitis C not be a primary consideration for
a second National Hepatitis C Strategy.

2002 Review of Strategic HIV/AIDS, Hepatitis C and Indigenous Sexual Health
Research and the National and Collaborating Centres in HIV Research

The Strategy Research Review Team recommends as follows:

89. That the outgoing Director of the National Centre in HIV Virology Research be
congratulated for the Centre’s excellent work in carrying out important,
internationally recognised research that is of very high quality and significance.

90. That the National Centre in HIV Virology Research, under the leadership of a
Director, develop a strategic plan for the duration of its current funding cycle. This
plan should guide the Centre’s progress towards obtaining competitive funding; it
should also include the important core research work (research that is highly strategic
but may not necessarily be innovative). The strategic planning process should involve
all stakeholders, including the HIV/AIDS advisory structure and the Department of
Health and Ageing.

91. That scientists in the National Centre in HIV Virology Research review areas of
commonality between the hepatitis C and human immunodeficiency viruses and their
immunovirology and strengthen links with virologists working on hepatitis C in
Australia and elsewhere. Where appropriate, funding could be sought for this research
through the competitive grant processes.

92. That the National Centre in HIV Social Research and the Australian Research Centre
in Sex, Health and Society be congratulated for their high-quality, internationally
recognised work in HIV social research.

93. That—where it is possible, feasible and appropriate—the National Centre in HIV
Social Research and the Australian Research Centre in Sex, Health and Society
engage with National Centres on Drug Research when doing work relating to injecting
drug users.

94. That the Director and Deputy Director of the National Centre in HIV Epidemiology
and Clinical Research be congratulated for their outstanding achievements in HIV
epidemiology, surveillance and clinical research.

95. That block funding for the National Centre in HIV Virology Research cease at the end
96. That a process be developed and funds be identified for purchasing ‘core research’ in HIV virology and immunovirology.

97. That a process be developed and funds be identified for purchasing a networking and communication function for research in HIV virology and immunovirology and that this function be placed with one of the laboratories or institutions that has received funding for the core research.

98. That there be no restrictions on National Centre in HIV Virology Research researchers applying for NHMRC or Australian Research Council funding as a result of receiving funding for core research or the networking function.

99. That the researchers currently involved in the National Centre in HIV Virology Research be encouraged to apply jointly for funding for the ‘core research’ and networking function.

100. That the researchers currently involved in the National Centre in HIV Virology Research be supported and encouraged to develop expertise in obtaining competitive funding to pursue innovative investigator-initiated research.

101. That the Population Health Division of the Department of Health and Ageing continue to fund the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society for at least the next five years—initially, through a new five-year funding agreement.

102. That a new process for determining the research priorities of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society, drawing in other researchers and stakeholders, be developed.

103. That both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society be encouraged to nurture social research outside Sydney and Melbourne through collaborative projects and mentoring. This would include developing HIV social research expertise outside the two major Centres.

104. That both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society—and the former in particular—pursue their host universities for increased support, in recognition of the kudos they bring to their hosts.

105. That the processes of funding and administering the funding of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society remain with the Population Health Division of the Department of Health and Ageing. Should the Department choose to transfer this function to another body, however, the conditions specified in recommendations 101 to 104, and any others that may be identified by the advisory structure in consultation with the two Centres, should still be met.

106. That the Population Health Division of the Department of Health and Ageing continue to fund the National Centre in HIV Epidemiology and Clinical Research for at least the next five years—initially, through a new five-year funding agreement.
107. That the National Centre in HIV Epidemiology and Clinical Research pursue its host university for increased support, in recognition of the kudos it brings to its host.

108. That the National Centre in HIV Epidemiology and Clinical Research explore ways of expanding the reach of its expertise—particularly in communicable diseases surveillance and in conducting clinical trials in the primary care setting—into other areas of concern to the Population Health Division.

109. That the Population Health Division continue to provide the National Centre in HIV Epidemiology and Clinical Research with additional funds for hepatitis C surveillance and that these funds be rolled into the Centre’s core funding.

110. That the processes of funding and administering the funding of the National Centre in HIV Epidemiology and Clinical Research remain with the Population Health Division. Should the Department choose to transfer this function to another body, however, the conditions specified in recommendations 106 to 109, and any others that may be identified by the advisory structure in consultation with the Centre, should still be met.

111. That strategic hepatitis C research be acknowledged as central to the Australian response to hepatitis C. Processes should be set up and resources allocated accordingly.

112. That the Population Health Division explore with the NHMRC and the Australian Research Council ways of funding a program of hepatitis C research over a long-term time frame, such as through Partnership funding.

113. That the Department of Health and Ageing explore ways in which research into the sexual health of Indigenous Australians, as well as hepatitis C and HIV in this population, can be supported and funded through appropriate mechanisms, integrating this with the current reform agenda in Aboriginal research that is being developed nationally.

114. That the Population Health Division resume dialogue with AusAID with a view to obtaining funding support for Australian researchers to work in HIV-related research in the Asia–Pacific region.

115. That the Population Health Division explore ways of accessing research expertise to assist with the management of a research program, including developing priorities for research and translating the research results into policy and practice.

116. That the Clinical Trials and Research Committee of ANCAHRD be abolished and a revised advisory structure be formed, with HIV/AIDS, hepatitis C and Indigenous sexual health committees having a mixture of policy and research expertise. The advisory structure’s overarching body should have only minimal influence on the work of these committees.

117. That there be a triennial time frame for setting research priorities in the areas of HIV/AIDS, hepatitis C and the sexual health of Indigenous Australians. All the relevant stakeholders should be involved in deciding the priorities, and the process should include a review of research undertaken to that time.
118. That the research priorities determined for each three-year period be communicated to the NHMRC and the Australian Research Council, with a view to influencing funding decisions. The priorities should be used to assess the significance of competitive grant applications in the areas of HIV/AIDS, hepatitis C and Indigenous Australians’ sexual health.

119. That, wherever possible, competitive funding sources be used for funding priority research and that core funding provided to the Centres be used for research that is of the highest priority and/or would be unlikely to be funded through competitive processes.

120. That the NHMRC, the advisory structure replacing the Clinical Trials and Research Committee, and the Population Health Division of the Department review the practice of restricting competitive grant applications by the Centres, with a view to removing the restrictions in the light of the processes recommended here.

121. That the role of the Centres’ Scientific Advisory Committees be strengthened and broadened to include overseeing, monitoring and communication tasks. The name ‘Scientific Advisory Committee’ might need to be changed to reflect this.

2002 Quinquennial Review of the National Centre in HIV Virology Research

The following is recommended:

122. That the National Centre in HIV Virology Research be sustained beyond 2003, with a nodal structure, as part of a strategic approach to the international HIV/AIDS epidemic.

123. That, following the resignation of the current Director, effective 31 December 2002, an interim Director be appointed for the transition period, who will be asked to maintain the scientific excellence at the Centre and to support the scientific staff, in collaboration with the incoming Director of the Burnet Institute.

124. That the interim Director be chosen from among the current principal investigators of the Centre.

125. That new applications for core support of the Centre be opened up for competitive bidding within the wider HIV virology and immunology community.

126. That the appointment of a new Director be incorporated in the new application process.

127. That responsibility for hepatitis C strategy research remain outside the terms of reference of the National Centre in HIV Virology Research and that an alternative mechanism be established to earmark funding for hepatitis C virology research.

128. That the HIV virology core research by the Centre be clearly defined, as outlined in this report, and that contracts for provision of this service very clearly describe the work required and the reporting structure.

129. That the role of the Scientific Advisory Committee be strengthened to oversee and monitor both strategic planning and scientific standards, and to provide regular written reports to ANCAHRD.
130. That services provided by the Centre, as outlined in this report, be incorporated in an annual work plan and include support for overseas collaborations and immunovirology monitoring for clinical studies of the molecular characterisation of HIV.

131. That links between this Centre, clinical groups and the National Centre in HIV Epidemiology and Clinical Research be fostered.

132. That Dr Stephen Kent’s formal linkage to the Centre be a priority for the future.

133. That an administrative mechanism be established that allows scientists providing core virology services ‘under contract’ access to peer-reviewed grant support, including from the NHMRC.

134. That administrative arrangements for the Centre beyond 2003 be clearly defined and transparent from the outset.

2002 Quinquennial Review of the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society

The following is recommended:

145. The Panel considers that the future social research program at both the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society would benefit from more formalised planning in a number of areas:

- in relation to funding sources and conditions, the identification of priority fields for research and the need to achieve a balance between research in HIV/AIDS, hepatitis C and sexual health in both the Indigenous and general populations

- clearer demarcation of research effort between the two Centres in relation to their respective strategic strengths and track records in the production of high-quality research

- processes for undertaking international work in a coordinated fashion.

146. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society continue to build on their respective research strengths, both substantively and methodologically, in a complementary and collaborative fashion.

147. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage exploration of joint activities such as publications, conferences and seminars, senior researcher training and development, new forms of community liaison, and induction for new research staff.

148. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage fuller involvement of their senior researchers in joint planning processes.

149. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society prepare explicit statements dealing with joint agreements between the two Centres and ensure the dissemination of these statements.
150. That, with a view to promoting research-career development, the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society encourage the introduction of a rolling program of career and professional development for staff at all levels in both organisations. Such a program could include emphasis on the provision of support and mentoring for publication and the development of a staff exchange program within and between the various components of the HIV/AIDS social research programs, at these Centres and elsewhere.

151. That existing mechanisms for accountability and scientific direction, including the Scientific Advisory Committees, be retained. Efforts should be made to encourage joint planning with respect to the development of research programs, inclusive of the respective Scientific Advisory Committees of both the Centres.

152. That the National Centre in HIV Social Research and Australian Research Centre in Sex, Health and Society develop systematic policies for striking the best balance in relation to publication of research results—including consideration of formalising systems for encouragement and support for publishing and setting annual targets for staff at different levels in each Centre.

153. That the host institutions for both Centres give consideration to the creation of a greater number of stable research positions.

154. The Panel recognises that liaison with government is a two-way process, but pursuit of a clearer and more coherent relationship with AusAID would be a distinct advantage to both Centres. Beyond this, and to further augment the two Centres’ capacity to work outside Australia, development of stronger relationships with UN agencies should become a priority.

2002 Quinquennial Review of the National Centre in HIV Epidemiology and Clinical Research

The following is recommended:

145. That a third level of management in the Centre be introduced.

146. That the Scientific Advisory Committee be streamlined, so that it provides the scientific guidance the Centre needs and that alternative mechanisms be explored for expanding the contribution of collaborators, stakeholders and other experts to the Centre’s work.

147. That in the next five years the Centre receive core funding that takes into account annual inflationary costs and the Centre’s expanding surveillance functions (see also recommendation 151).

148. That the Centre identify or develop national expertise in anti-retroviral pharmacology to support this area of research.

149. That the Centre conduct trials in hepatitis C–infected injecting drug users in collaboration with providers of their long-term care.

150. That the Centre explore, through further national and international collaboration, use of its unique repository of specimens on HIV-infected patients.
151. That the small amount of additional core funding for hepatitis C and B surveillance be extended for five years, taking into account annual inflationary costs. Expansion into the area of STIs, with improvements in the quality of data, will require additional core funding.

152. That support be sought from AusAID for expansion of the program in the Asia–Pacific region and preparation for the vaccine work. It may be necessary for the Centre to work with other groups in Australia who have a longer history of working experience in developing countries.

153. That the Centre continue to expand its work on Indigenous Australians’ health, including hepatitis C, through its work with the Indigenous Australians’ Sexual Health Committee and in collaboration with other research and health service provider organisations with expertise in Indigenous health.

154. That discussions begin between the Centre and the University of New South Wales to redefine their relationship, with input from other appropriate authorities. These discussions should take into account the long-term vision for the Centre.

155. That the Centre consider changing its name in the light of its current and future activities.
9.1 GLOSSARY

Acquired immunodeficiency syndrome (AIDS)

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

AIDS Councils

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

Anti-retroviral

An agent that is active against a retrovirus. In this context, any medication that is designed to inhibit the process by which HIV replicates.

Australasian Society for HIV Medicine (ASHM)

Australasian Society for HIV Medicine Inc. is the peak Australasian organisation representing the medical and health sectors in HIV/AIDS and related areas.

Australian Federation of AIDS Organisations (AFAO)

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

Australian Hepatitis Council (AHC)

The Australian Hepatitis Council is the leading national agency for people with hepatitis C and other chronic viral hepatitis.

Australian Injecting and Illicit Drug Users League (AIVL)

The Australian Injecting and Illicit Drug Users' League (AIVL) is the national peak organisation representing the State and Territory Drug User Organisations, and issues of national significance for illicit drug users. AIVL is a peer-based organisation which means that it is run by and for illicit drug users.

Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD)

The Commonwealth Government’s key advisory body on HIV/AIDS and Hepatitis C, established to provide independent and expert advice to the Minister of Health and Ageing on the implementation of the National HIV and Hepatitis C Strategies. It is principally concerned with the identification of national needs, objectives and priorities and takes a public information role in matters related to HIV/AIDS and hepatitis C issues.
Australian National Council on AIDS and Related Diseases (ANCARD)

The predecessor to ANCARHD, this was the Commonwealth Government’s key advisory body on HIV/AIDS.

Basic scientific research

Develops knowledge, techniques and expertise that can be applied to research into specific disease processes and the development of population health policies and interventions.

Best practice

On the evidence available, the best intervention to produce improved outcomes for an identified problem.

Blood-borne virus

A virus that may be transmitted via blood or body fluids that contain blood. Such transmission can result from sharing injecting equipment.

Clinical research

Health research relating to individual patients as well as the development and evaluation of treatments for diseases.

Clinical trial

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

Cohort study

A research method whereby the same individuals are studied over time.

Co-infection

In this context, the term used to describe the circumstance in which a person is concurrently infected with hepatitis C and another blood borne virus such as HIV.

Combination therapy

The use of two or more types of treatment in combination, alternately or together, to achieve optimum results and reduce toxicity.

Communicable diseases

An illness caused by a specific infectious agent or its toxic products and that arises through transmission of that agent or its product from an infected person, animal or other reservoir to a susceptible host.
Communicable Diseases Network Australia (CDNA)

The Communicable Diseases Network Australia (CDNA) is a Commonwealth body with representatives from the Commonwealth, State/Territory health agencies and other Government and research bodies. CDNA meets on a regular basis and keeps track of disease outbreaks within Australia and New Zealand.

Community development

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

Culturally appropriate

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

Custodial setting

Refers to the various settings in which adults and juveniles can be detained or imprisoned.

Demand reduction interventions

Interventions designed to reduce the desire for and preparedness to obtain and use illicit drugs. Such interventions seek to prevent the uptake of harmful drug use and include abstinence-oriented interventions aimed at reducing illicit drug use and drug related harm.

Deoxyribonucleic acid (DNA)

The chemical inside the nucleus of a cell that carries the genetic instructions for making organisms.

Discrimination

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

Epidemiology

The study of the distribution and determinants of health-related states or events in specified populations and the application of the knowledge thus gained to deal with health problems.
Evidence-based practice

Involves integrating the best available evidence with professional expertise to make decisions.

Gay man

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

Genotype

A term used to classify the RNA genome of the hepatitis C virus according to the nucleotide sequence of defined regions of the genome.

Harm minimisation

The primary principle underpinning the National Drug Strategic Framework; the term refers to policies and programs aimed at reducing drug-related harm. Underlying the principle is the intention to improve health, social and economic outcomes for both the community and the individual. A wide range of approaches are involved, including abstinence-oriented strategies. Both licit and illicit drugs are the focus of Australia’s harm-minimisation strategy. Harm minimisation includes preventing anticipated harm and reducing actual harm. It is consistent with a comprehensive approach to drug-related harm, involving a balance between demand reduction, supply reduction and harm reduction.

Harm reduction interventions

Interventions designed to reduce the impacts of drug related harm on individuals and communities. Governments do not condone illegal risk behaviours such as injecting drug use; they acknowledge that these behaviours occur and that they have a responsibility to develop and implement population health measures designed to reduce the harm that such behaviours can cause.

Health maintenance

In this context, promoting approaches, interventions and lifestyle choices that support continued management and monitoring of a person’s health with the intention of reducing the severity and side effects of chronic hepatitis C infection and deferring the onset of advanced liver disease.

Hepatitis C virus (HCV)

An RNA virus transmitted through blood-to-blood contact.

Highly Specialised Drugs Program

Provides access (as Pharmaceutical Benefits Schedule items) to certain medicines for chronic conditions that because of their clinical use or other characteristics are restricted to supply through hospitals having access to appropriate specialist facilities.
Homosexually active man

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

Human immuno-deficiency virus (HIV)

A human retrovirus that leads to AIDS.

Illicit drug

A drug whose production, sale or possession is prohibited

Incidence

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

Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD)

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

Mainstreaming

An approach to service delivery characterised by a move from specialist HIV/AIDS services towards increasing the capacity of the entire system to deliver appropriated services.

National Association of People Living with HIV/AIDS (NAPWA)

The peak national organisation representing people who are HIV positive.

National Public Health Partnership (NPHP)

A broad, multilateral intergovernmental framework that enables a cooperative approach to the improvement of the population health system and clarifies the roles and responsibilities of its principal partners. Membership consists of senior health officials from the Commonwealth and each State and Territory, the Australian Institute of Health and Welfare and the National Health and Medical Research Council.

Needle and syringe programs (NSPs)

Programs authorised to distribute, dispose of or sell needles and syringes.
Parliamentary Liaison Group

A non-partisan forum through which information is provided to members of the Commonwealth Parliament and in which policy discussions can occur.

Peer education

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

Pharmacotherapy

The use of pharmacological agents to treat disease. In this context, the use of HIV antiretrovirals.

Prevalence rate

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

Prophylaxis

Any measure taken to prevent an adverse outcome from occurring. In this context, prescribing medication that is known to prevent an infection from taking hold at a time when a person may not be infected or ill but is at risk of developing that infection or illness.

Public Health Outcome Funding Agreements (PHOFAs)

The PHOFAs provide broadbanded funding to States and Territories to support their role in the achievement of nationally agreed outcomes in population health. States and Territories have the flexibility to use this Commonwealth assistance according to local needs and priorities, whilst ensuring that specific outcomes are met.

Retrovirus

A virus that inserts a DNA copy of its genome into the host cell in order to replicate. HIV is a retrovirus.

Ribonucleic acid (RNA)

A chemical similar to a single strand of DNA. In RNA, the letter U, which stands for uracil, is substituted for T in the genetic code. RNA delivers DNA’s genetic message to the cytoplasm of a cell where proteins are made.

Safe sex, safe sexual practice

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

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

Sexually transmissible infection

An infection—such as HIV, gonorrhoea, syphilis or chlamydia—that is transmitted through sexual contact.

Shared care

Arrangements for providing a continuum of health care where care and advice are shared between primary care physicians and specialists such as gastroenterologists, hepatologists or infectious diseases specialists.

Social and behavioural research

Research designed to identify the social and behavioural factors that affect disease transmission with the aim of enabling the development of specific interventions for specific groups. Social research also identifies support networks and quality-of-life factors to be considered in population health policies.

Supply reduction interventions

Interventions designed to disrupt the production and supply of illicit drugs.

Surveillance

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

Viral load

The amount of virus present per cubic millilitre of blood, as measured by a viral-load test.

Virology

The science of investigation of virus structure, mode of action and disease processes and the identification of possible interventions at the cellular level. Developments in virological research can also contribute to the development of drug and vaccine therapies.
10.1 ABBREVIATIONS

**AFAO** *Australian Federation of AIDS Organisations*

AHC  Australian Hepatitis Council

AHMC  Australian Health Ministers’ 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

ANCARD  Australian National Council on AIDS and Related Diseases

ANCD  Australian National Council on Drugs

ARC  Australian Research Council

ARCSHS  Australian Research Centre for Sex, Health and Society

ASEAN  Association of South East Asian Nations

ASHM  Australasian Society for HIV Medicine

AusAID  Australian Agency for International Development

CARG  Commonwealth AIDS Research Grants

CDNA  Communicable Diseases Network Australia

CHRN  Community HIV Research Network

CTARC  Clinical Trials and Research Committee

CTTAC  Clinical Trials and Treatments Advisory Committee

DAD Study  Data Collection on Adverse Events of Anti-HIV Drugs Study

DNA  deoxyribonucleic acid

HAART  highly active anti-retroviral therapy

HBV  hepatitis B virus

HCV  hepatitis C virus

HIV  Human Immuno-Deficiency Virus
IDU injecting drug user/injecting drug use
IGCAHRD Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases
MHC major histocompatibility complex
MoU Memorandum of Understanding
NAPWA National Association of People Living with HIV/AIDS
NCHECR National Centre in HIV Epidemiology and Clinical Research
NCHSR National Centre in HIV Social Research
NCHVR National Centre in HIV Virology Research
NGO Non-Government Organisation
NHMRC National Health and Medical Research Council
NIH (US) National Institutes of Health
NPHP National Public Health Partnership
NSP Needle and Syringe Program
PBS Pharmaceutical Benefits Scheme
PHOFA Public Health Outcome Funding Agreement
PLATO Study Performance of Lopinavir/Ritonavir as an Alternative Treatment Option Study
PLWHA People Living with HIV/AIDS
PLWHAC People Living with HIV/AIDS and their carers
R&D Research and Development
RAC Research Advisory Committee
RNA ribonucleic acid
SAC Scientific Advisory Committee
SAVINE scrambled antigen vaccine
SMASH Sydney Men and Sexual Health
STD sexually transmitted disease
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>STI</td>
<td>sexually transmissible infection</td>
</tr>
<tr>
<td>TAR</td>
<td>Tat responsive element</td>
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<tr>
<td>Tat</td>
<td>transactivation of transcription</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<tr>
<td>UNGASS</td>
<td>UN General Assembly Special Session on HIV/AIDS</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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