

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

THE ROAD NOT TAKEN

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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.

Governance and partnerships

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.

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. Surveillance 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.

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.

People from culturally and linguistically diverse backgrounds

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.

Treatment, care and support

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.

Rural and regional settings

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.

Custodial settings

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.

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.

The Strategy builds on the achievements of the National Hepatitis C Action Plan (Australian Health Ministers Advisory Council 1994), the Nationally Coordinated Hepatitis C Education and Prevention Approach (Hepatitis C Education and Prevention Reference Group 1995) and successive national HIV/AIDS strategies, including the current National HIV/AIDS Strategy 1999–2000 and 2003–04. This

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

3.3.2 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.

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).

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.

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)⁵

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

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:

Identify and analyse strategic links with other National Strategies, including the National HIV/AIDS Strategy 1999–2000 to 2003–2004, the National Indigenous Australians' Sexual Health Strategy 1996–97 to 1998–99 (as extended) and the National Drug Strategic Framework 1998–99 to 2002–03, having regard to the quality, strength and extent of those links.

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.
 7. Identify and analyse strategic links with other National Strategies, including the National HIV/AIDS Strategy 1999–2000 to 2003–2004, the National Indigenous Australians' Sexual Health Strategy 1996–97 to 1998–99 (as extended) and the National Drug Strategic Framework 1998–99 to 2002–03, having regard to the quality, strength and extent of those links.
 8. Examine the transferability of approaches, partnerships, principles and services in hepatitis C to other chronic diseases.
 9. Examine the impact of hepatitis C in the Asia-Pacific region and the need for international assistance and cooperation in respect of hepatitis C.
 10. Identify any:
 - ◆ new or shifting priorities; and/or
 - ◆ gaps in implementation; and/or
 - ◆ barriers to achieving sustained control of hepatitis C in Australiawhich 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.

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